



Rhode Island Resource Guide for Families of Children with Autism Spectrum Disorders

OFFICE OF FAMILIES RAISING CHILDREN WITH SPECIAL HEALTH CARE NEEDS

APRIL 2006

NOTE TO PROFESSIONALS: THIS IS A VALUABLE RESOURCE FOR YOU AS YOU WORK WITH FAMILIES.

MAKE HE[♥]ALTH PART OF YOUR FAMILY
RHODE ISLAND DEPARTMENT OF HEALTH

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INTRODUCTION

Welcome to the Rhode Island Resource Guide for Families of Children with Autism Spectrum Disorders (ASDs). This guide was developed by a committee of experts on ASDs spearheaded by the Rhode Island Department of Health's Office of Families Raising Children with Special Health Care Needs. Committee members include physicians, members of community service organizations, and parents of children with ASDs.

Like many parents of children who have been diagnosed with an ASD, you may be feeling overwhelmed. You may be concerned about your child's developmental progress, about whether your child received an appropriate diagnosis, and about what your next steps should be. Help is available.

This Rhode Island Resource Guide provides information for families at different stages of the ASD diagnosis process, to assist them in finding help for their children and family support. Information detailed in this guide includes:

- » The signs and symptoms of ASDs and their effect on child development
- » Adjusting to your child's diagnosis
- » Health Coverage Assistance
- » Treatments and interventions
- » Educational services
- » Community resources and other family supports

At this point, you may have been to a number of doctors and specialists, seeking diagnosis for your child. You are doing the right thing. Early and appropriate diagnosis can help guide your choices and can lead to better outcomes for your child. Having a specific diagnosis of an ASD can sometimes open doors to services that would otherwise be closed. It is important to remember that only professionals experienced in the diagnosis and management of ASDs can accurately make the diagnosis. Developmental pediatricians, child neurologists, child psychologists, or child psychiatrists usually diagnose ASDs. Other professionals who can help clarify the diagnosis can include speech and language pathologists, occupational therapists, physical therapists, geneticists, audiologists, educators, and special educators.

It is not simple to diagnose a child with an ASD, since there are no medical tests to detect it. Doctors may use several medical tests to “rule out” other conditions and disorders, such as hearing loss, mental retardation, and speech problems. Doctors who specialize in ASDs may use several kinds of tools to determine whether a child has an ASD—from rating scales and

checklists to observing the child's speech and behavior. They also need detailed information about the child's behavior and early development. To make a diagnosis, doctors must see clear evidence of poor social and communication skills and behavioral concerns before age three. Children with an Autism Spectrum Disorder usually have some problems in each area.

Most children with an ASD show signs of the disorder(s) in infancy. Recognition of difficulties with social relationships, communication, and imaginative thought is essential for early diagnosis and intervention. Children with an ASDs are usually identified sometime between 18-24 months of age, with the exception of Asperger Disorder, which has a later onset.

For parents and family members, learning that your child has an ASD can be very difficult. During the diagnosis process, you may feel isolated and alone. It is important to remember that these feelings are normal. Seeking support from your partner, family, and friends can be helpful. Other parents with children with ASDs can also be valuable resources. Additionally, there are many local and national organizations that you can access to learn more about ASDs.

As you learn about ASDs and begin to use the resources and support available to you, you will feel more in control, and your family's life will begin to take shape. The more knowledge that you gain, the more empowered you will become to take on an advocacy role for your child. Remember, you are the most important advocate for your child.



Welcome to Holland

by *Emily Pearl Kingsley*

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you are going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum, the Michelangelo David, the gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, “Welcome to Holland.”

“Holland?” You say, “What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy.”

But there has been a change in my flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole different language. And you will meet a whole new group of people you never would have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you have been there for a while and catch your breath, you look around, and you begin to notice that Holland has windmills, Holland has tulips, Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy, and they're all bragging about the wonderful time they had there. And for the rest of your life, you will say, “Yes, that's where I was supposed to go. That's what I had planned.”

The pain of that will never, ever go away, because the loss of that dream is a very significant loss.

But if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things about Holland.

Understanding Autism Spectrum Disorders

DEFINING AUTISM SPECTRUM DISORDERS (ASDs)

Autism Spectrum Disorders (ASDs) are considered to be neurological disorders, which means that they affect how the brain functions. ASDs affect each child differently, to different degrees of severity. However, all children with ASDs share difficulties in 3 areas: social interaction, communication and repetitive behaviors. Two children with the same disorder can act differently and can have different skills. A child's ability to learn and think can vary from being gifted to being severely challenged. Some children who are mildly affected may show only slight delays in language and more difficulty with social skills. A child with an ASD may have average to above average verbal, memory, or spatial skills, but may find it hard to be imaginative or to participate in activities with his or her friends. Other children may be more severely affected and may need more help with day-to-day activities.

THE DISORDERS WITHIN THE AUTISM SPECTRUM

The term Autism Spectrum Disorder is not a specific diagnosis. It is a general term that includes the following diagnoses: Autistic Disorder, Asperger Disorder, and Pervasive Developmental Disorder (including the less common Childhood Disintegrative Disorder and Rett's Disorder).

There are no specific medical tests for diagnosing ASDs. An accurate diagnosis should be based on observation of a child's behaviors, communication, social skills, and developmental level. A diagnosis of an ASD, or any other developmental disability, is based on the Diagnostic and Statistical Manual of Mental Disorders-Fourth Edition (DSM-IV), published by the American Psychiatric Association. This is the main diagnostic tool used by mental health professionals in the United States. See Appendix C for the diagnostic criteria from the DSM-IV that professionals use to diagnose children with ASDs.

Following are descriptions of each disorder:

AUTISTIC DISORDER

Children with Autistic Disorder have trouble forming normal social relationships and communicating with others. They may also have a limited range of activity and interests. Children with Autistic Disorder vary greatly. Autistic Disorder is sometimes referred to as Early Infantile Autism, Childhood Autism, Classic Autism, or Kanner's Autism. Autistic Disorder affects boys more often than girls.

ASPERGER DISORDER

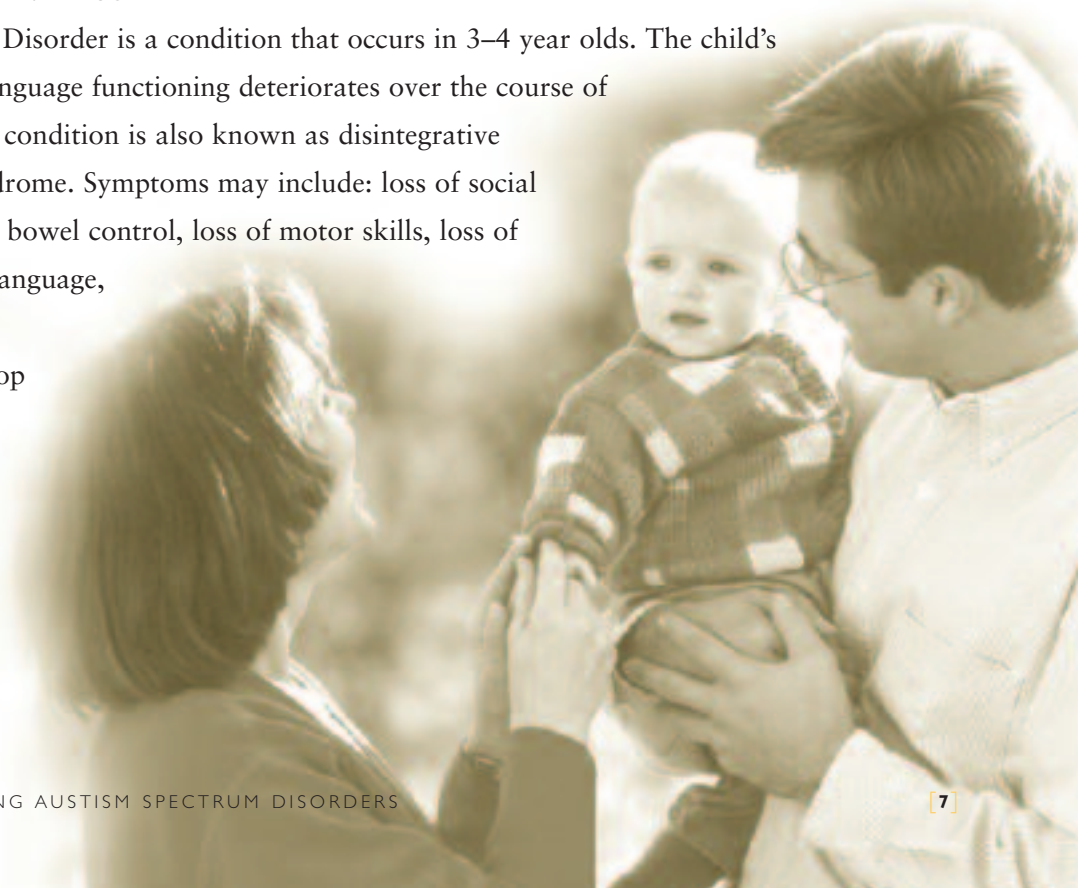
Asperger Disorder is a relatively new diagnosis that affects boys more than girls. Most children with Asperger's have normal intelligence and early language development. However, they have severely impaired social skills and are unable to communicate effectively with others. Many children with this disorder have poor coordination or repetitive speech, problems with reading, math or written skills, odd behaviors or mannerisms, obsession with specific topics, and a lack of common sense.

PERVASIVE DEVELOPMENTAL DISORDER—NOT OTHERWISE SPECIFIED (PDD-NOS)

PDD-NOS is also called atypical autism or mild autism. Children with PDD-NOS usually have severe impairment in several areas of development, including social interaction and communication skills. It is a neurological disorder diagnosed when children have many features of autistic disorder, but do not meet the full criteria.

CHILDHOOD DISINTEGRATIVE DISORDER

Childhood Disintegrative Disorder is a condition that occurs in 3–4 year olds. The child's intellectual, social, and language functioning deteriorates over the course of several months. This rare condition is also known as disintegrative psychosis or Heller's Syndrome. Symptoms may include: loss of social skills, loss of bladder and bowel control, loss of motor skills, loss of receptive and expressive language, delay or lack of spoken language, failure to develop peer relationships, lack of play, inability to initiate or sustain a spoken conversation, and impairment in nonverbal behaviors.



Danny's Story

The following story by Stephanie, a mother who suspected her son had an ASD, describes the steps she took to get a diagnosis.

Our son Daniel was born in late July of 2000. Danny, as we call him, grew and developed appropriately. He was chubby and sweet and had an infectious belly laugh...still does. Once he learned to crawl he couldn't wait to tackle climbing. He was also doing the typical babbling and saying DADADA among other jargon. I remember thinking he would be saying DADA very soon. That never happened.

By Danny's first birthday, I became concerned. He seemed to change. He was withdrawn and silent. I could put him to bed and he wouldn't even try to get up. As I started to investigate, I realized he wasn't pointing or waving goodbye. At his 12-month check-up I shared my concerns with his pediatrician and he felt everything was fine. I was still nervous so I contacted Early Intervention. We had an initial visit with Early Intervention and a subsequent evaluation from a speech therapist. We then decided a neurological evaluation was necessary to rule out specific medical conditions. Danny had several tests including an MRI and BEAM (similar to EEG) and every chromosomal test you can imagine. All results were normal.

I had done so much research on my own, but I couldn't decide what the problem was. In my opinion, he presented with many symptoms of autism but I couldn't get professionals to confirm. I joined a local support group when he was 16 months old because I knew other mothers would point me in the right direction. They did. I put his name on a waiting list for speech and occupational therapy at a local hospital. At 18 months, we were able to secure an evaluation. We left with a diagnosis of Mixed Developmental Delay, which was not very helpful.

When Danny was 22 months old, we were finally referred to the Groden Center's Early Intervention program, which proved invaluable. They came to our home one time per week to work with Danny. Danny also attended a playgroup a couple of times a week at the Center. I met people with whom I needed to connect, and things started to come together. We finally received his diagnosis when he was two years old. At 27 months, Danny started an ABA-based home program.

There are so many key elements, but the best advice I could give is to trust your instincts and be involved with your child's therapy. No one wants his or her child to be labeled as anything but perfect. The day you receive a diagnosis might be the worst day of your life but the best day for your child as it opens up doors to services he or she may not otherwise be entitled to. Your child's therapy is your responsibility and being involved, knowing your therapists, and being familiar with your child's programs can only be beneficial to your child. Be sure the people you choose are committed to your child and do everything you can to make them feel welcome in your home. Remember, it's a team effort, and you are a huge part of the team.

It's a very long, difficult road, but we love our son dearly and want him to be the best he can possibly be. First and foremost, he is a little boy. A little boy who works over 40 hours a week and has done so since he was two years old. This is not what we had in mind, but it is what it is and we will continue to do everything in our power to help him. It's a process that constantly evolves. It requires flexibility and determination. His triumphs, however small or large, are the highlights of our lives, and his struggles break our hearts. We pray for a cure and hope it comes in time to help Danny. But in the meantime, we love him unconditionally and that is something a diagnosis of any kind will never change.

RETT'S DISORDER

Rett's Disorder is a genetic brain disorder, seen mostly in females (starting between 6 and 18 months of age), characterized by wringing of hands, slowed brain and head growth, walking abnormalities, seizures, and mental retardation. Symptoms may include toe walking, sleep problems, large or protruding teeth, wide-based walking (walking with feet far apart), and disorganized breathing patterns that occur when awake. A specific genetic test is now available to confirm a diagnosis of Rett's Disorder.

RELATED CONDITIONS

A number of overlapping conditions may occur with ASDs, or in some cases, may be confused with ASDs. These conditions can be grouped into four categories:

- » Genetic disorders—Angelman Syndrome, Fragile X Syndrome, Prader-Willi Syndrome, and Williams Syndrome;
- » Neurological conditions—Seizure Disorders and Tourette's Syndrome;
- » Psychiatric disorders—Anxiety Disorders, Obsessive Compulsive Disorder, Bipolar Disorder, Attention Deficit Disorder; and
- » Other learning disabilities and disorders—Attention Deficit Hyperactivity Disorder, Hyperlexia, Mental Retardation, Non-Verbal Learning Disorder, Oppositional Defiant Disorder, Semantic-Pragmatic Disorder.

Please see the Glossary for a description of these conditions. Most children with an ASD do not have these conditions.

HOW ASDs AFFECT CHILD DEVELOPMENT

Families are often the first to notice that their child is not achieving developmental milestones or to observe behaviors that are worrisome. Some families say that their baby seemed different from birth. Other families say that their child seemed to be developing normally before he or she began to show unusual behaviors or to not develop as expected. A diagnosis of an ASD is based on seeing a child's behavior or symptoms in social relationships, social communication, and imaginative thought. Each symptom can range in severity from mild to severe. The following are possible ways that an ASD may affect child development:

SOCIAL RELATIONSHIPS

A child may spend more time alone rather than with others, may show little interest in making friends, and may be less responsive to social cues such as eye contact, universal body language, or smiles. Other characteristics may include, but are not limited to:

- » Not wanting to hug or cuddle;
- » Being detached from the feelings of others;
- » Not imitating others;
- » Being unaware of emotions of others; and
- » Lacking spontaneous sharing of interest with others.

SOCIAL COMMUNICATION

A child does not develop speech or another method of communicating, such as pointing or gesturing. A child may have speech at first and then may lose it. Other symptoms may include:

- » No babbling by one year of age, no single words by 16 months, no two word phrases by 24 months;
- » Not responding to his or her name or verbal cues—may act as if deaf although his or her hearing tests in the normal range;
- » Appearing to not understand simple requests;
- » Difficulty expressing needs and concepts;
- » Repeating words or phrases (called echolalia) instead of using normal language; and
- » Speaking on narrowly-focused topics (for example, always talks about the same topic like numbers, letters, trains).

REPETITIVE BEHAVIORS

A child may be very focused on one interest or topic. A child may also lack spontaneous or imaginative play, not imitate other's actions, or not initiate or participate in pretend games. Other symptoms may include:

- » Being too attached to objects;
- » Obsessive unusual play with toys or objects (may line them up or spin them);
- » Disliking changes in routine or environment (e.g., change in daily tasks or schedule, things moved somewhere else); and
- » Unusual body movements (hand flapping or spinning).

SENSORY SENSITIVITY

For children with an ASD, sensory sensitivity is common. This can result in a child's senses (sight, hearing, touch, smell or taste) being over- or under-active. Behaviors that may indicate that a child has sensory sensitivity include:

- » Covering ears (sensitivity to the sound of noise);
- » Becoming stiff when held (sensitivity to the feeling of touch);
- » Removing clothes often (sensitivity to the feeling of fabric on the skin);

- » Refusing to eat certain foods (sensitivity to food textures);
- » Putting objects close to nose to smell (sensitivity to smells); and
- » Becoming non-responsive or hyperactive in noisy or bright environments.

OTHER CHARACTERISTICS

- » Having frequent temper tantrums for no apparent reason;
- » Showing no fear of danger;
- » Hitting or biting self or others; and
- » Not reacting to pain.

Families can find more information about child developmental milestones on the Centers for Disease Control and Prevention (CDC) website at www.cdc.gov/actearly.

Learn the Signs. Act Early.

WWW.CDC.GOV/ACTEARLY • 1-800-CDC-INFO

IT'S TIME TO CHANGE HOW WE VIEW A CHILD'S GROWTH.

As they grow, children are always learning new things. These are just some of the things you should be looking for as your child grows. Because every child develops at his or her own pace, your child may reach these milestones slightly before or after other children the same age. Use this as a guide, and if you have any concerns, talk with your child's doctor or nurse.

BY THE END OF 7 MONTHS, MANY CHILDREN ARE ABLE TO:

- » Turn head when name is called
- » Smile back at another person
- » Respond to sound with sounds
- » Enjoy social play (such as peek-a-boo)

BY THE END OF 1 YEAR (12 MONTHS), MANY CHILDREN ARE ABLE TO:

- » Use simple gestures (waving "bye-bye")
- » Make sounds such as "ma" and "da"
- » Imitate actions in their play (clap when you clap)
- » Respond when told "no"

BY THE END OF 1½ YEARS (18 MONTHS), MANY CHILDREN ARE ABLE TO:

- » Do simple pretend play (“talk” on a toy phone)
- » Point to interesting objects
- » Look at object when you point at it and tell them to “look!”*
- » Use several single words unprompted

BY THE END OF 2 YEARS (24 MONTHS), MANY CHILDREN ARE ABLE TO:

- » Use 2- to 4-word phrases
- » Follow simple instructions
- » Become more interested in other children
- » pPoint to object or picture when named

BY THE END OF 3 YEARS (36 MONTHS), MANY CHILDREN ARE ABLE TO:

- » Show affection for playmates
- » Use 4- to 5-word sentences
- » Imitate adults and playmates (run when other children run)
- » Play make-believe with dolls, animals, and people (“feed” a teddy bear)

BY THE END OF 4 YEARS (48 MONTHS), MANY CHILDREN ARE ABLE TO:

- » Use 5- to 6-word sentences
- » Follow 3-step commands (“Get dressed. Comb your hair, and wash your face.”)
- » Cooperate with other children

QUESTIONS TO ASK YOUR CHILD’S DOCTOR OR NURSE:

- » What can I do to keep track of my child’s development?
- » What should I do if I’m worried about my child’s progress?
- » Where can I go to get more information?
- » Can you refer me to a specialist for more information?

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**Baird, G., Charman, T., Baron-Cohen, S., Cox, A., Swettenham, J., Wheelwright, S., and Drew, A. (2000). A Screening Instrument for Autism at 18 Months of Age: A 6-Year Follow-up Study. J. Am. Acad. Child Adolesc. Psychiatry, 39:694–702.*

CAUSES OF ASD

Researchers are working on finding ways to prevent, diagnose, and treat ASDs and related conditions in children. There are many theories about why more children are being diagnosed with ASDs. The most common theories are that there are both genetic and environmental components and that this is possibly a re-classification of children previously thought to have other diagnoses.

GENETIC FACTORS

Genetics, or the study of genes, may provide some insight into the causes of ASDs. Our genes are found in nearly every cell of our bodies, and they control the body's growth and functioning. Half of our genes are inherited from our fathers and half from our mothers.

TALKING WITH A GENETICIST

Talking with a geneticist (a doctor who specializes in genetic conditions) may be recommended to help find the cause of an ASD. The visit usually involves a complete patient history, a family history (known as a pedigree), a complete physical examination, and appropriate blood tests. Families who receive a specific diagnosis can then receive genetic counseling about the chances that an ASD might appear in another family member in the future.

ENVIRONMENTAL FACTORS

Some people believe ASDs are caused by environmental factors. There are various theories that link environmental factors with ASDs, none of which have been proven by research. These theories include birth trauma, toxins, dietary factors, and immunizations. Without scientific support or professional agreement, the Rhode Island Department of Health does not endorse any of these theories.

Most professionals would agree that:

- » 0.6% or (1 in 166) of children are diagnosed with an ASD.
- » Abnormalities of the chromosomes have been found in 6–8% of children with ASDs.
- » When a family has one child with an ASD, the chance it will happen to future children is between 4–8%.
- » Males are affected 3–4 times more frequently than females.
- » In identical twins, if one is affected, there is a very high chance that the second twin will be affected as well.

Most children with ASDs (90–95%) have “idiopathic” ASD, meaning that the cause is still unknown. Researchers are working hard to identify the genes associated with idiopathic ASDs. The other 5–10% of children have “secondary” ASDs, which means that there is a cause.

MORE ABOUT ASDs

THE ORIGIN OF THE TERM “AUTISM”

The term “autism” and “autistic” comes from the Greek work autos, meaning self, and was first used by the psychiatrist, Eugene Bleuler, in 1911. Later in 1943, Leo Kanner, an Austrian psychiatrist at John Hopkins University, again used the term “autism” to describe children with specific behaviors he identified as a neurological condition. Around the same time, an Austrian pediatrician in Vienna named Hans Asperger, who was studying children with similar behaviors, also used the description of “autistic” in 1944. Both doctors associated the term “autism” with specific features seen in children in the areas of communication, social interaction, and behaviors. Since then, doctors have learned much more about autism’s wide spectrum of behaviors and connected the many myths associated with this disorder.

COMMON MYTHS ABOUT ASDs

MYTH: INSIDE EVERY CHILD WITH AN ASD IS A GENIUS.

Famous people including Ludwic Van Beethoven, Isaac Newton, and Albert Einstein have been identified as possibly having had an ASD. Although it is true that some children with an ASD do have IQ scores at the genius level, most do not. Children with an ASD have a full range of IQ scores, just like typical children.

MYTH: EVERY CHILD WITH AN ASD HAS A SPECIAL TALENT.

There are children with an ASD who do have a special talent. Most children, however, do not. Many children with an ASD have uneven abilities—they may do well in one area, such as math, but don’t do as well in another area, such as social communication.

MYTH: CHILDREN WITH AN ASD DO NOT HAVE EMOTIONS AND ARE NOT ABLE TO FORM ATTACHMENTS WITH OTHERS.

Children with an ASD do have feelings, but they may express them differently. Research shows that children with an ASD can form attachments to important people in their lives.

MYTH: CHILDREN WITH ASDS ARE NOT ABLE TO COMMUNICATE.

Many children with an ASD have language skills. Others can learn to communicate through the use of gestures, picture exchange, sign language, spoken language, and computer technology. (See section 4 for more information about these interventions.)


MYTH: CHILDREN WHO HAVE AN ASD DON’T MAKE EYE CONTACT.

Many children who have an ASD do make eye contact. Eye contact can also be taught to children who have difficulty looking at another person’s face.

A Grandparent's Perspective

Autism—just the word brings anxiety and fear with stereotypical thoughts of a mute child beyond human contact in a world of his own, or a “Rain Man” type autistic savant with amazing powers in some areas but woeful inadequacies in most other aspects of life. A diagnosis brings more questions than answers and eventually an awareness of the broad spectrum involved. One fact that has recently received national media attention is that 1 in 166 children have autism. It is an equal opportunity attacker affecting all socio-economic levels.

My heartfelt wish is that my seven grandchildren will experience lives full of love, faith, hope, and fulfillment. I bring many years as an early childhood educator to my role as a grandparent. In my profession, I frequently advised parents to have children tested and evaluated after noticing early signs of something out-of-sync developmentally. Regarding my own grandson, my previous professional experience and intuition seemed to evaporate. I was in denial of the “red flags” indicating a problem. Fortunately that period of denial was short-lived. I soon realized that my darling grandson, like all children who manifest early warning signs, required testing,



evaluation and a team of experts to address his specific needs. Fortunately, my grandson has benefited from the efforts of dedicated medical and educational professionals starting with the Early Intervention program. The work of the many professionals in my grandson's life has been complimented by the love and support of family and friends. All of us are working to unravel some of the mystery surrounding the depth and breadth of autism.

My grandson has been blessed with a mother dedicated to becoming as knowledgeable as possible in dealing with autism. As a result of her research, expertise and ability, she has become a tireless advocate for her son's needs and those of other children and families dealing with the frustration and challenges in their daily lives. Our family is inspired by her efforts.

As a grandparent, I continue to learn as much as I can about autism. In spite of my fear, I am confident that we will find answers to the questions. Increased public awareness, first-hand experiences, and the heroic efforts of all who have helped my grandson inspire hope for the future.

In the past few years, I have witnessed amazing growth, emotionally, socially, and cognitively in my grandson. His empathy towards others, his eye contact, his ability to spell difficult words, his sense of humor, his interest and ability in reciprocal play, and asking for another kiss and hug rather than resisting physical contact are some of the many little miracles offering hope for his future. How fortunate I am to be the grandparent of a dear child full of potential, mystery, a very different way of looking at the world and such a beautiful smile!

Adjusting to your Child's Diagnosis

Parents often spend the time before getting their child's diagnosis walking an emotional tightrope between hope and despair—wanting to believe that their child's development is typical but feeling that something does not seem right. Learning that your child has an ASD is difficult to accept. It is perfectly normal for you to grieve for your child and for yourself. The dream of having a “perfect” child seems lost, and you are not sure of your child's and family's future. It is hard to accept that your child is not doing the same things or reaching the same milestones as typical children. But it is important to remember that your child is still the same child that he or she was before receiving his or her diagnosis. Your child still loves you and needs you now more than ever.

DON'T OVERWHELM YOURSELF WITH INFORMATION

Many parents of children with an ASD have said to not collect too much information about ASDs too early after receiving the diagnosis. While you should eventually collect all the information you need, don't overwhelm yourself in the beginning.

The Internet can be a good resource for information; however, keep in mind that not everything on the Internet is reliable or accurate. If you type the word “autism” into a search engine, you may find the volume of information overwhelming, and in many cases, outdated. The websites listed in the Community Resources and Websites Section of this guide may be helpful as you begin collecting information.

ALLOW YOURSELF TO GRIEVE

Many parents of children who have been diagnosed with an ASD will never forget how it felt when they heard the words, “Your child has an Autism Spectrum Disorder.” At first, the diagnosis may not seem believable. Families grieve in different ways. Some parents hold everything inside, and others look for support. There is no right or wrong way to grieve. Some families say that the grief they felt after they got their child's diagnosis was like the grief of losing a loved one. Many parents talk about experiencing a rollercoaster of emotions, such

Our Children Have Much to Teach Us

Learning that your child has an ASD brings up many different emotions for families. For many parents, this is a time of uncertainty and stress. Sammi, the mother of a boy with autism, shares some of the feelings that she had during this time:

One of the hardest things in life is to learn of the troubles or challenges that your children may face as they grow. Whether they are physically, emotionally, or neurologically impaired (or perhaps all three), we too suffer with our children.

One of the most important things that we must do is not only see their disability. Autism, in itself, is actually invisible most of the time. Our children do not look different; however, after a short period of observation, it becomes apparent that they are, in fact, very different. They are not badly behaved, nor are they defiant; their disability and their frustrations that result from their inability to communicate are what cause these “behaviors” to surface. Our children can feel love and be loved, and we MUST love them...more unconditionally (if possible) than others. Perhaps we did nothing to deserve them; however, we have been chosen to raise them. We will become better parents—better people—because of them. We will acquire a new tolerance for those with difficulties and disabilities; we will be more sensitive to those who struggle, whom we may not have noticed otherwise. We will stop to lend a hand, for we know that our children may need a random act of kindness bestowed upon them at one time or another.



as disbelief, shock, relief, denial, sadness, fear, and anger. Many parents also expressed feeling overwhelmed and powerless. They had a million questions about how to help their child, but they did not know where to turn for the answers. ASDs are a mystery, and it is natural to feel fear and uncertainty.

As a child with an ASD develops, families cycle through the different stages of grief, or they are at different stages of grief at different times. Each birthday, family gathering, or holiday may bring up feelings of anger, guilt, and sadness when you see the differences between your child and other children. Many families express that they feel like their world has shattered or that their world has come to an end. But in time, they may see that it is not the end. It is just different.

THE FIVE STAGES OF GRIEF

All these emotions are normal. Below is Elizabeth Kubler-Ross' (*On Grief and Grieving*, Scribner, NY, 2005) description of the five stages of grief: denial, anger or resentment, bargaining, depression, and finally acceptance.

Denial

In this stage, parents may react with shock and may not believe the diagnosis. Many parents may think: "Not my child, the doctors are wrong;" "My child didn't know the people who tested him;" or "My child will outgrow it when he is older." Denial is a common reaction to life-changing news, and it is actually a healthy response that helps a person take in bad news and find a way to cope with it.

Anger or Resentment

Parents in this stage may question why this is happening to their child. They may direct their anger at the doctor, at other professionals, or at a higher power (if they have certain religious beliefs). Some parents may even be angry with themselves. They may feel guilty that, somehow, they were responsible for the diagnosis. It is important to understand that these feelings and thoughts are common, and they are an important step in the grieving process.

Bargaining

In this stage, parents may bargain with themselves or a higher power (if they have certain religious beliefs). They may think: "I will give or do such and such if my child's condition improves." At this stage, parents are beginning to see that their child has ASD, and are trying to find a way to cope with the information.

Depression

Parents in this stage are beginning to understand that the diagnosis is not going away, and

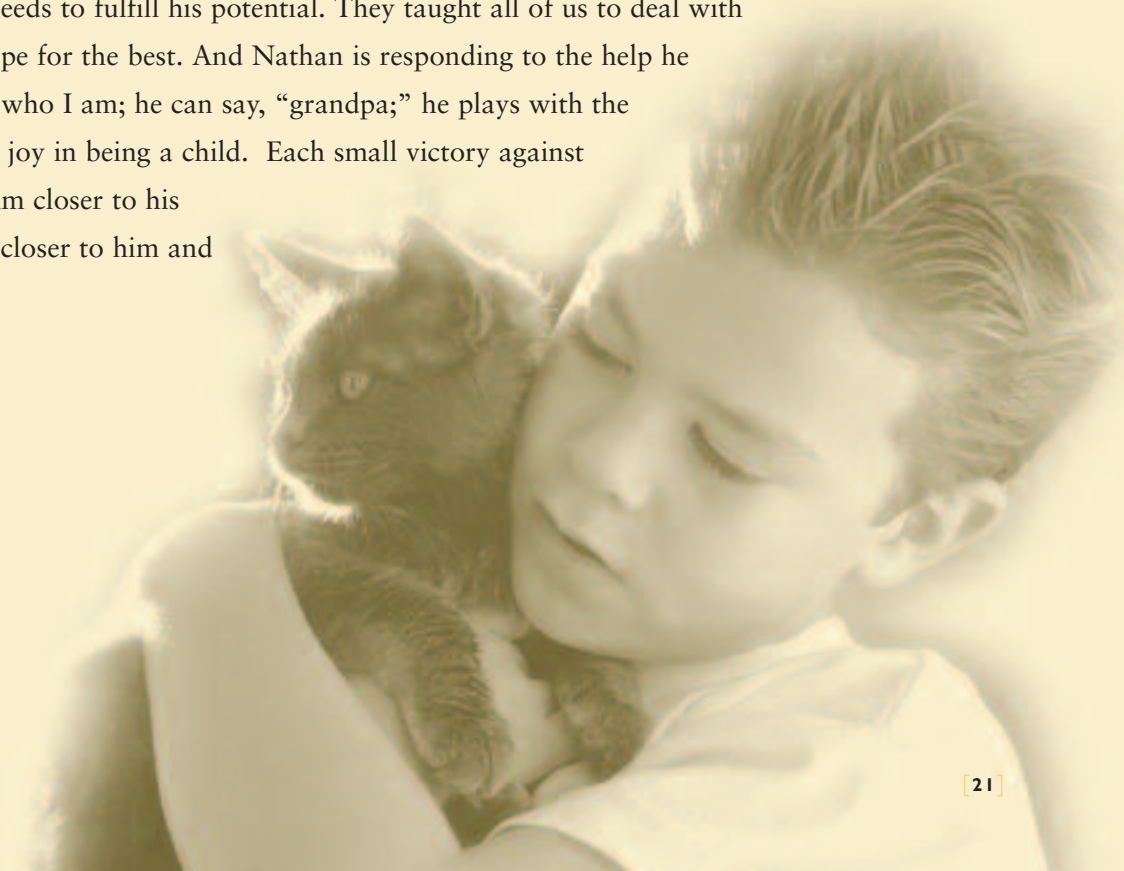
Nathan's Story

The following story written by a grandfather tells of the many challenges that faced his daughter's family faced when his grandson, Nathan, was diagnosed with an ASD.

My grandson Nathan was less than a year old when I began to suspect he had developmental challenges. He seemed to be in his own world, unable to interact with me at almost any level. There was no discernible recognition of me when I visited and no visible joy or interest in the toys and games I brought as gifts. Thus, the diagnosis of his being on the autistic spectrum was not a surprise. The diagnosis, however anticipated, was still an event filled with dismay and questions, questions, questions. What was his potential? Would he ever talk? Could he ever be mainstreamed? How would this affect my daughter and her family? Could they handle the enormous pressures and demands? What would happen to Nathan after I was gone and his parents' no longer living?

For all of the articles and on-line research, the thousands of paragraphs and millions of words written about autism, my questions could not be answered. Everyone in the family was "at sea." Feelings were raw and emotions high. Some days, it felt as if we were in mourning. Now, it is almost 3 years after the diagnosis and the turmoil that followed.

My daughter and son-in-law have risen to the challenge far better than I could have ever dreamed. They sought good advice. They worked tirelessly to get Nathan the services, therapy and help he needs to fulfill his potential. They taught all of us to deal with the realities and to hope for the best. And Nathan is responding to the help he is getting. He knows who I am; he can say, "grandpa;" he plays with the toys I bring and takes joy in being a child. Each small victory against this disorder brings him closer to his family and his family closer to him and to each other.



they can begin to admit it to themselves. Admitting that their child has a lifelong disability can make people feel very strong emotions, such as sadness, fear, and loss. It is important to recognize that these feelings are completely normal, and expressing them is a part of the grieving process.

Acceptance

This is the last stage in the grieving process. Some parents will arrive at this stage earlier or later than others. Accepting your child for who he or she is, and maybe more importantly, for who he or she is not, is difficult. It is important to recognize how difficult acceptance can be and to remember that parents are grieving for their lost child. It is important to remember during the acceptance process that you are not alone.

BE YOUR CHILD'S NUMBER ONE ADVOCATE

Being a parent or guardian is the most important job anyone could have. All children are dependent on their caregivers for everything. As a parent or guardian, you serve as your child's number one role model. The activities and experiences you expose your child to depend on the level of effort you put into your job as a primary caregiver.

Parenting a child with an ASD is very challenging. Your child needs constant therapies and services other children do not. It is your job to find those services, to coordinate them, and to monitor how they are working. Many parents of children with an ASD find that their life's mission is to help their child reach his or her full potential. They rise to the challenge and find that making sure that their child gets the best care and support possible is very rewarding. As you begin your journey as a caregiver of a child with an ASD, remember that you and your child are a team, and you are his or her number one advocate.

HOW TO HELP YOUR FAMILY ADJUST

Many families raising children with an ASD say that they feel stress in different parts of their lives, including family relationships, finances, employment, and mental or physical health. Family participation in activities in the community may also be affected.

Walk With Me...

Written by Sally Meyer, 1999

*Walk in my shoes for one single day.
Then you will see why I need to pray.
Come live in my home for a week or two,
And then remember I am just like you.
I didn't ask for the things I was given.
I didn't choose this road I have taken.
Walk with me hand in hand,
And then perhaps you will understand.*

*I am really not complaining about the stress in my life,
I know that we all have strife.
But walk with me, when you think I am wrong,
Walk with me and you'll start to belong.*

*Embrace my sorrows, like they are your own,
And then you will know me and see I have grown.*

*The journey I take is different from yours—
My life took one of those unexpected detours.
But this road that I travel is not really so long,
If the people who watch me will join my song.
Listen to my footsteps and watch as I dance,
And then you will know me and give me a chance.*

*Take heart and remember it can happen to you,
Who knows where my pathway will cross over to you?
So speak to me softly if you can understand—
Remember I once stood where you stand.
And walk with me gently when the day is at end,
And then I will call you my friend.*

When a child has an ASD, the entire family is affected. Day-to-day routines may need to be changed. Life is no longer what the family knew prior to receiving the diagnosis. A grocery store visit, a doctor's appointment, a haircut, a birthday party—these are all activities that families can do with their typical children without worry or cause for adjustment. But for parents of children with an ASD, these ordinary events can be very stressful. It is important to remember that your goal is to help your child learn the social skills he or she needs to interact successfully with people in the community.

New experiences are very difficult for children with an ASD because they like routine, structure, and consistency. A change in routine often creates tension and worry for the child. As difficult as it is, taking small steps and being persistent will eventually lead to the child's adjustment to a new routine.

It is hard for families when their child acts differently than what is socially accepted. Families find it hard to deal with their child throwing a tantrum out in public, and they are always afraid that this could happen at any moment. Since children with an ASD typically look like other children, some people may make insensitive comments about how your child is behaving. These comments can be very hurtful, and they may make you angry. Some things you can do to cope with this are:

- » Carry a card with the definition of ASDs written on it. Reach into your pocket, don't speak, and show them the card.
- » Talk about your feelings with your partner, neighbor, or a good friend.
- » Call another parent who has a child with an ASD for support.
- » Contact an ASD support group.
- » Talk to one of your child's doctors, therapists, or teachers about your feelings.

HELPING SIBLINGS COPE

An ASD is not always easy for siblings to understand. The attention that a child with an ASD needs from caregivers can really impact siblings in the family. To siblings, children with an ASD look as healthy and as “normal” as other kids. This makes it hard for siblings to understand how their brother or sister behaves and why he or she gets special treatment from you and from others. Some siblings may adjust well, while others may feel jealous, embarrassed, or angry. There are many ways that families can help siblings adjust. Being aware of the siblings' concerns and needs is important. Some ways that you can help siblings cope are:

Teach Siblings Open Communication

Most parents want their children to talk to them openly. Some siblings are open and honest with their parents. They let their parents know how having a sibling with an ASD affects their lives. Other siblings may keep their feelings to themselves. Sometimes, this is just a part of their personality. Other times, siblings may not want to bother their parents with their problems or they may feel guilty about their own feelings. Siblings learn to express their feelings and to share their thoughts by watching how adults express their feelings and how adults deal with emotional situations. Being calm and honest when talking about your own feelings, both when you are happy and upset, is a good model that encourages siblings to talk about their feelings. Listening calmly to siblings when they talk, without judging what they say, will encourage them to come to you when they have questions or concerns about their brother or sister.

Explain ASDs to Siblings in Simple Terms

Siblings need basic information about ASDs. Siblings need to understand that an ASD affects how children learn, how they play, and how they get along with others. It is helpful for siblings to learn that they did not cause an ASD and that they cannot “catch it” or get it later in life. Siblings should also be given basic information about how their brother or sister's condition is being treated. When explaining ASDs to young siblings, parents should be calm, should use simple words, and should focus on a few pieces of information at a time.

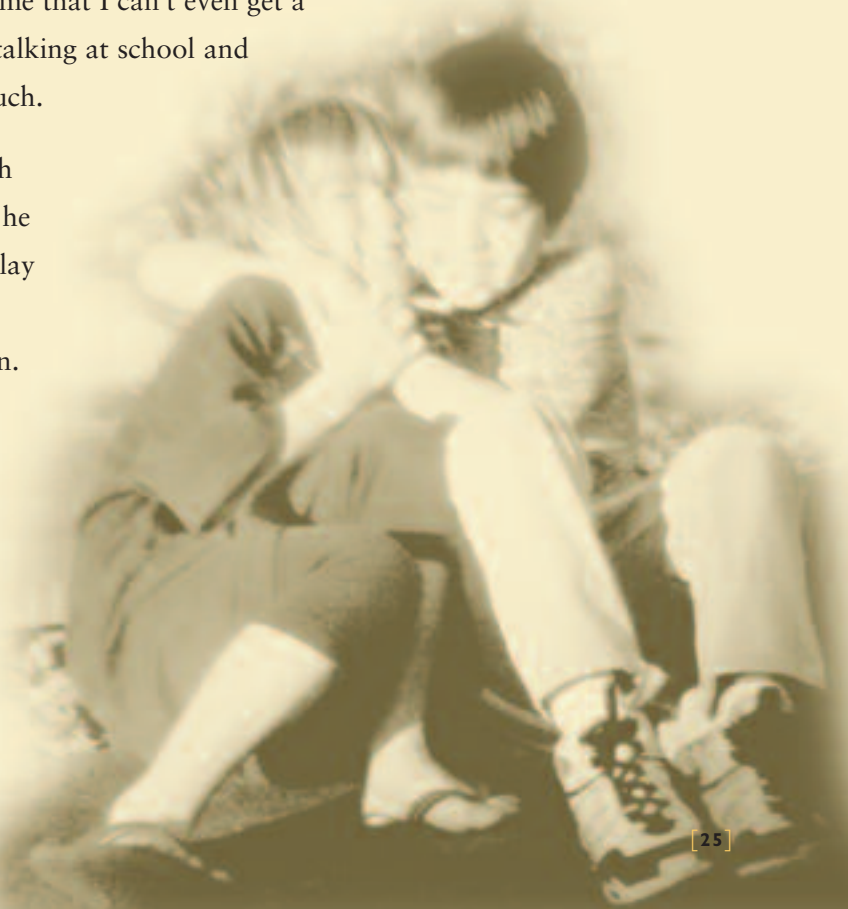
How My Brother With Asperger Affects My Life

I hope this article helps kids who have brothers or sisters with special needs know that they are not the only ones with siblings with disabilities. I want to make other kids feel better because I thought I was the only one in the world who had a sibling with special needs.

I am 10 years old and my brother is 12 years old and has Asperger. Being his brother is both difficult and easy so you could basically say I have mixed emotions.

First I will tell you the difficult things. One of them is that when we go in public my brother usually makes a scene and embarrasses me by acting inappropriately. There is nothing I can do about it. I can't often have friends over because he is mean to them and acts like he is three years old. So some of them think he is stupid and others understand that he has difficulties acting appropriately because he has special needs. He makes me so mad sometimes that my sadness and anger carries over to school, which affects my school work and behavior. He needs so much direction and attention at home that I can't even get a word in. Consequently, I have to do all my talking at school and my teacher gets mad at me for talking so much.

The good things about having a brother with Asperger is when I ask him to play with me he always says yes. Another great thing is we play pretend games and he has an awesome imagination which makes the games very fun. Sometimes he is so caring that when it's my birthday or Christmas, he wants to get me the best present out of everyone in the family. He is always willing to help me with things I need like homework or video games. Most importantly no matter what, he always says I am his best friend and I feel the same way about him.





Focus on Treating Each Child Fairly

At some point, most children complain that their parents are not being “fair.” Siblings of children with an ASD are more likely to say this when their parents let the child get away with something for which the sibling would be punished, or when the sibling cannot do something because of his or her brother or sister. Siblings know that parents spend more time with their brother or sister, and they are likely to say that this is unfair if parents do not seem to take special time alone with the sibling.

It is simply not possible to treat two different children equally. Instead of trying to treat all children equally, try to treat each child fairly. As you will soon learn, fair is not always equal. Try to treat each child according to his or her needs and wants. Make sure all children, including the child with an ASD, are expected to do something to contribute to the family life, like helping around the house and helping each other.

Allow Independence and Individual Time for Siblings

All children like to feel that they are unique and loved by their family. It is easy for siblings to feel like they do not get enough attention because of their brother or sister’s special needs. While it is great to do things as a family, it is also normal for siblings to want to have their

own friendships and to do activities that interest them. Allow siblings to attend some of their own activities, separate from those of their brother or sister. Siblings and parents also need their own special time alone together. A special date with a sibling alone to focus on who that child is as an individual is usually as enjoyable for parents as it is for siblings. These dates do not have to be long or complicated. Ten minutes of undisturbed special time together each day goes a long way in letting siblings know that they are special too.

Help Siblings Get Support

Siblings of children with an ASD may feel that their friends do not understand their situation. Some siblings feel afraid that other children will tease them or that they will not want to be their friends because of their brother or sister. It is helpful for siblings to hear other kids with brothers or sisters with an ASD talk about their good and bad experiences. Meeting other brothers and sisters of children with special needs helps siblings understand that they are not alone—that there are other great kids out there who know exactly how they feel.

Encourage siblings to participate in special sibling activities organized through the child's school or through an ASD organization. SibLink at Hasbro Children's Hospital is a program that was created to meet the needs of brothers and sisters of children with all special needs, including those with ASDs. SibLink offers services to families on an individual and group basis. All groups are educational, supportive, and fun. For more information, please refer to the Community Resources and Websites Section of this guide.

STEPS TO PROVIDE SAFETY IN THE HOME

While every child is different, many children with ASDs have no sense of danger and can be impulsive. A child with an ASD may not respond to his or her name when called or may run into traffic even if you scream, "STOP!" This is because he or she does not understand what "STOP" means. Children with ASDs may not understand danger and may often wander off. Because of this, it is very important to make your home and your child's environment safe. These suggestions for making your home a safer place may help to protect your child with an ASD:

- » Put a fence around your backyard and/or your pool;
- » Attach safety locks on windows and doors, gates on stairs, guardrails on your child's bed, and childproof latches on cabinets;
- » Make sure that small objects are out of your child's reach and that you know how to give CPR and First Aid;
- » Use audio monitors throughout your home; and
- » Make sure that someone is always watching your child.

* Note: Children with an ASD are often attracted to water sources such as pools, ponds, and lakes. Drowning is the leading cause of death for children with ASDs. As a result, many families register their children in swimming classes for both recreation and safety.

OTHER STEPS YOU CAN TAKE TO INCREASE SAFETY FOR YOUR CHILD:

1. *Put together an informational handout for your local police department and a neighbor(s) whom you can trust.* Explain your child's condition to them, and give them your handout. Your handout should include your child's picture, weight, height, any distinguishing marks, address, and your home telephone, cell phone, pagers, and work phone numbers. It should also indicate how your child communicates (e.g., sign language, picture exchange, or non-verbal). If your child cannot speak, an identification bracelet with his or her name, address, and home phone can be very useful. Inform your child's school that he or she will be wearing this bracelet and that it is not to be taken off. More information on identification jewelry can be found on the American Medical ID website at www.americanmedical-id.com.
2. *Have your child's medical information readily accessible.* Hasbro Children's Hospital in Providence has a medical alert system called the Frequent Flyer program for children with special health care needs. This system stores all of your child's medical information in a database that can be quickly accessed in the event of an emergency. Families can contact the Frequent Flyer program at Hasbro Children's Hospital to ask about registration. When your child's registration is confirmed, provide this information to your child's caretakers, school, and anyone else who needs to know. This program is provided at no charge to families. More information about this program is listed in the Resource Section of this guide.
3. *Consider applying for handicapped street signs for your neighborhood.* You can get these from your town or city administrator. You can also get a handicapped license plate or a placard from the Department of Motor Vehicles.
4. *Decrease the chance of accidents happening in the home by labeling potentially dangerous items (e.g., the oven, iron, or refrigerator) with signs that say NO or STOP.*

A Different Kind of Hero

Janine, a mother of a boy with an ASD, provided a story that her 12-year-old daughter wrote about her brother for an annual contest sponsored by her school.

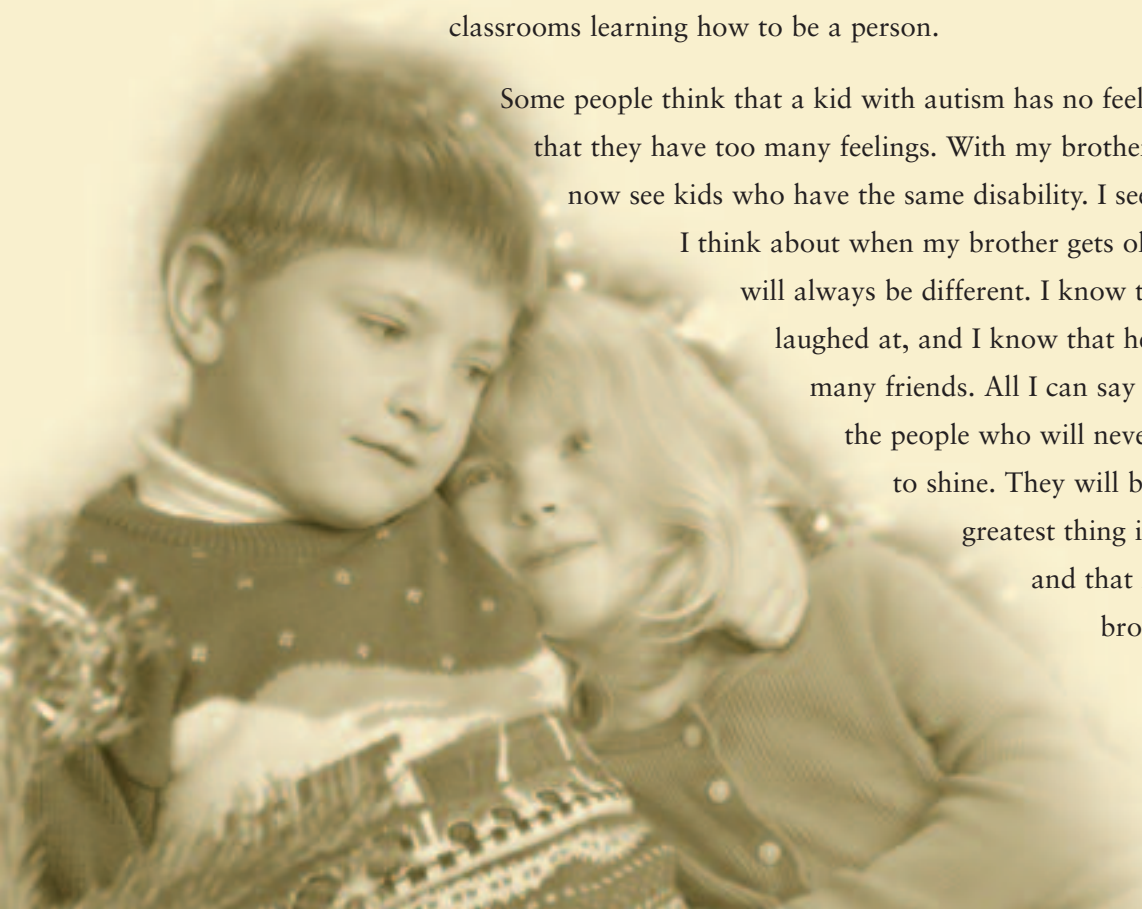
Every day he gets up. He has to be helped to the bathroom. He needs to be cleaned and eating breakfast is really hard. He hates to eat; sometimes just smelling food makes him gag. He smells everything. He gets dressed with help, and then they come to our house or he gets on a school bus and he goes with them. They teach him how to walk, how to use a fork and spoon, how to speak and how to look at you when you call his name.

He has no friends, but he is always busy. He hardly talks, but most of the time when the phone rings it is for him. I am talking about my baby brother. He is 3 years old. I am 12. Even though I am older, I look up to him now, and I probably always will. He is my different kind of hero. He has autism.

Every day is a struggle for him to learn how to do the things we do. Like going to the bathroom. Putting on your clothes, eating a bowl of cereal, or just saying good morning. Instead of getting to play with a bunch of kids like other three year olds, he is busy inside classrooms learning how to be a person.

Some people think that a kid with autism has no feelings. Not true. I say that they have too many feelings. With my brother in my life I can now see kids who have the same disability. I see how it is for them.

I think about when my brother gets older, and I know he will always be different. I know that he will get laughed at, and I know that he will not have many friends. All I can say is I feel sorry for the people who will never give him a chance to shine. They will be missing out on the greatest thing in the whole world and that is simply...him, my brother with autism.



Steps after Diagnosis

After your child has been diagnosed with an Autism Spectrum Disorder (ASD), some of the first issues or questions you will want to consider include:

1. ASSISTANCE: How will I provide for my child's care? What does my insurance cover? What type of assistance is my family eligible for through state or federal programs? Where should I start looking?

First Steps:

- » Check with your health insurance to see which services are covered.
- » Contact a community family support service (listed in Community Resources and Websites section) to learn about the different assistance programs that are available and whether your child would qualify to receive these services.
- » Explore Medical Assistance/Medicaid services.

2. TREATMENTS AND SERVICES: Which treatments and services will my child need? How do I find out what's best for my child? Where do I find these services?

First Steps:

- » Talk to your doctor or the diagnosing physician about your child's options.
- » Contact the Rhode Island Early Intervention program and/or CEDARR Family Center for help determining which treatments and services may be best for your child.

3. EDUCATION: What issues do I need to consider in terms of my child's education?

First Steps:

- » If your child is under age three, enroll your child in the Rhode Island Early Intervention program.
- » Early Intervention can help your child transition to the public school system for special education services (if eligible) or another appropriate community program/service.
- » If your child is over age three, contact school officials and formulate a plan with school professionals.

MEDICAL ASSISTANCE (MEDICAID)

If your child has been diagnosed with an ASD, you are probably concerned about handling the financial costs of your child's care. Check with your health insurance carrier to find out which services are covered by your insurance. Additionally, Medical Assistance, also called Medicaid, could be an invaluable resource to you, and it should be one of the first resources that you investigate.

Medical Assistance, also called Medicaid, is a federal and state program that was created in 1956 by Congress under the Social Security Act. Medicaid programs are jointly funded by the federal and state governments and are administered by each individual state. In Rhode Island, the Rhode Island Department of Human Services is the state agency responsible for administering the Medicaid Program. Medicaid should not be confused with Medicare, which is a federal insurance program. For more information on Medicaid, please visit the United States Department of Health and Human Services website at www.cms.hhs.gov/medicaid.

Medicaid programs pay for services identified in a plan called the State Plan. Within Medicaid is a program for children birth to 21 years of age called the Early and Periodic Screening Diagnosis and Treatment (EPSDT) Program. Under this program, children receive screening and diagnostic services as well as any medically necessary treatments that may not be available under a state's Medicaid plan but are allowed under federal Medicaid law. The EPSDT Program ensures that Medicaid benefits for children are the same across the delivery systems.

Families and children in Rhode Island may be eligible for Medical Assistance by applying for coverage through the following:

- » RItE Care (Rhode Island's Medicaid managed care program)
- » RItE Share Program
- » Supplemental Security Income (SSI) Program
- » Katie Beckett Eligibility
- » Adoption Subsidy

Descriptions of these programs, including contact information, are found further in this section of the guide (pages 34–36).

ELIGIBILITY/APPLICATION ASSISTANCE FOR FAMILIES (FAMILY RESOURCE COUNSELORS)

Family Resource Counselors (FRCs) educate families about which types of assistance they might be eligible for and can help them apply for programs. FRCs serve families statewide at no cost to the child or family. They are located at the community health centers and hospital clinics listed below.

Bayside Family Health Care, North Kingston, RI

Phone: (401) 295-9706

Blackstone Valley Community Health Care, Pawtucket, RI

Phone: (401) 722-0081

Chad Brown Health Center, Providence, RI

Phone: (401) 274-6339

Family Health Services, Coventry, RI

Phone: (401) 828-5335

Family Health Services, Cranston, RI

Phone: (401) 943-1981

Hasbro Children's Hospital/Rhode Island Hospital, Providence, RI

Phone: (401) 444-4000

Health Center of South County, Wakefield, RI

Phone: (401) 783-0523

Memorial Hospital, Pawtucket, RI

Phone: (401) 729-2634

New Visions for Newport County, Newport, RI

Phone: (401) 947-7821

Northwest Health Center, Harmony, RI

Phone: (401) 568-7661

Providence Community Health Centers

Allen Berry Health Center

Phone: (401) 444-0570

Capital Hill Health Center

Phone: (401) 444-0550

Providence Community Health Centers (continued)

Central Health Center

Phone: (401) 444-0580

Fox Point Health Center

Phone: (401) 444-0530

Olneyville Health Center

Phone: (401) 444-0540

St. Joseph's Health Services, Providence, RI

Phone: (401) 456-4029

Thundermist Health Associates, Woonsocket, RI

Phone: (401) 767-5444

Women and Infants Hospital, Providence, RI

Phone: (401) 274-1122

Self Help/East Bay Family Health Care, East Providence, RI

Phone: (401) 437-5101

Tri-Town Health Center, Johnston, RI

Phone: (401) 351-2750

Wood River Health Services, Hope Valley, RI

Phone: (401) 539-2461



RITE CARE PROGRAM

RIte Care is Rhode Island's Medicaid managed care program that provides eligible families and eligible uninsured pregnant women, parents, and children up to 19 years of age with health insurance coverage. Families receive most of their health care through one of three participating health plans: Neighborhood Health Plan of Rhode Island, United Healthcare of New England, and Blue ChiP.

Neighborhood Health Plan of Rhode Island
299 Promenade Street, Providence, RI 02908
Phone: (401) 459-6000 or (800) 963-1001
Fax: (401) 459-6066
Website: www.nhpri.org

Blue Cross/Blue Shield of Rhode Island
444 Westminister Street, Providence, RI 02903
Phone: (401) 459-2000
Website: www.bcbsri.com

United Healthcare of Rhode Island
475 Kilvert Street, Warwick, RI 02886
Phone: (401) 737-6900
Website: www.unitedhealthcare.com

RITE SHARE PROGRAM

RIte Share is a premium assistance program that helps low- and middle-income families obtain health insurance coverage through their employer (or spouse's employer) by paying all or part of the employee's share of monthly premiums. Under the RIte Share Program, individuals who are income eligible for Medical Assistance and are employed by an employer who offers a RIte Share-approved health plan can enroll in their employer's health insurance plan and receive assistance with premiums. The RIte Share Program will also pay all or part of the co-payments associated with the employer's health plan. For more information about RIte Care or RIte Share contact:

Rhode Island Department of Human Services
Center for Child and Family Health
600 New London Avenue, Cranston, RI 02920
Information Line: (401) 462-5300 (English or Spanish)
TTY: (401) 462-3363
RI Relay: 7-1-1
Website: www.dhs.ri.gov

SUPPLEMENTAL SECURITY INCOME (SSI) PROGRAM

Supplemental Security Income (SSI) is a federal program that provides health insurance monthly cash payments to individuals, including children (birth to 18 years of age) with physical, developmental and/or mental impairments that result in “marked and severe functional limitations.” If a child is eligible for SSI benefits in Rhode Island, he/she is also eligible to receive Medicaid (see RIte Care section above for more information). Children under the age of 18 with a physical, developmental and/or mental impairment may be eligible if their family also qualifies based on limited income and resources. After the age of 18, SSI benefits are based only on the income of the individual applying for SSI. For more information contact:

Social Security Office

380 Westminster Street, Room 318, Providence, RI 02903

Phone: (401) 528-4535 or (800) 772-1213

Fax: (401) 528-4698

Website: www.ssa.gov

KATIE BECKETT ELIGIBILITY

Katie Beckett is a special eligibility process that allows certain children under the age of 18 with significant disabling conditions to obtain RI Medical Assistance coverage. Eligibility is determined by the child’s income and resources (not the family’s) and a “level of care determination.” A level of care determination means that if the child was not living at home with Medical Assistance benefits/coverage, he or she would require care and services in a hospital, skilled nursing facility, or institutional setting. The cost of care provided at home must be less than what Medical Assistance would pay if the child were in a hospital or other institutional setting. For more information contact:

Rhode Island Department of Human Services

Long Term Care

600 New London Avenue, Cranston, RI 02920

Information Line: (401) 462-5300 (English or Spanish)

TTY: (401) 462-3363

RI Relay: 7-1-1

Website: www.dhs.ri.gov

ADOPTION SUBSIDY

Adopted children may qualify for an adoption subsidy, which includes a stipend and Medical Assistance. The Adoption Subsidy Program is administered through the Department of Children, Youth and Families. For more information, contact:

Rhode Island Department of Children, Youth and Families
Adoption Services Unit
101 Friendship Street, Providence, RI 02903
Phone: (401) 254-7021
Website: www.dcyf.ri.gov

MANAGED CARE FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Since 2003, Neighborhood Health Plan of Rhode Island has offered a specialized care management program for children with special health care needs. Some of the benefits include:

- » A Care Manager assigned to your family.
- » A comprehensive needs assessment completed within days of enrollment.
- » An integrated care plan including medical, behavioral health, social and dental care services.
- » Assistance in understanding and adhering to provider's treatment plans.
- » Facilitated access to all needed health care services and providers.
- » Communication and collaboration with other care providers (e.g., physical, occupational, speech therapists) and care coordinating organizations (e.g., CEDARR Family Centers).
- » Referrals to non-health care related services such as transportation and interpreters.



SERVICES

Two programs that can help you determine which services your child needs are the Rhode Island Early Intervention Program and CEDARR (CEDARR stands for Comprehensive, Evaluation, Diagnosis, Assessment, Referral and Re-evaluation).

RHODE ISLAND EARLY INTERVENTION PROGRAM

Each state is mandated to provide an Early Intervention Program for children with developmental delays (from birth to three years of age) in accordance with a federal law entitled the Individuals with Disabilities Education Act (IDEA). In Rhode Island, the Rhode Island Department of Human Services administers the Early Intervention Program.

Early Intervention (EI) is a family-centered program that promotes the growth and development of infants and toddlers with developmental challenges. EI serves all eligible children (from birth to three years of age) and their families, regardless of income or health insurance coverage. All EI sites provide services to children with ASDs and their families. Services are individualized to support and assist families in meeting the goals that they have for their child.

Referrals for a child who has an ASD or symptoms of an ASD can be made directly to EI programs by family members, guardians, primary care physicians, and community agencies for infant and toddler screening, evaluation, and assessment to determine eligibility for services. When a child is referred to EI, eligibility will be determined through an evaluation and assessment performed by the EI program. Some children are eligible based on their diagnosis. This includes children with an ASD diagnosis. The purpose of the evaluation and assessment process includes not only eligibility determination, but also information gathering for planning purposes and answering family questions regarding their child's development.

Individualized Family Service Plan (IFSP)

After a child is determined eligible for EI, the family works with a team of EI professionals to design a plan called the Individualized Family Services Plan (IFSP). This plan outlines the child's strengths and needs using the result of an evaluation or assessment and is developed based on the desired outcomes of the family. Families serve as key members of the team in the development of a plan to ensure that the plan is realistic and workable for both the child and the family.

The IFSP, once completed, will identify supports and services necessary for the child and family to achieve the outcomes. The IFSP is reviewed every six months or as needed.

Program Model

A key component of the EI model is the teaming of parents and professionals. Each family participating in Early Intervention is assigned a Service Coordinator. The Service Coordinator is responsible for coordinating the services in the IFSP. The Service Coordinator also serves as the single point of contact for the family to obtain services and to provide assistance as needed.

EI services are provided in natural environments to increase the child's participation in typical family and community activities and routines. Parent(s) and caregivers are involved in actual "hands-on" activities throughout the day, with the service providers acting as consultants, teachers, and coaches. Natural environments are the day-to-day settings, routines, and activities where a child would be if he or she had no disability and is where young children learn best.

Parent Consultants

Every EI Program has at least one Parent Consultant available to help families participating in the program. Parent Consultants have had personal experience with the EI Program; they can assist families with system navigation and can provide them with resources, support, and connections to other families. Parent Consultants work closely with the EI staff and provide the "family perspective." Their role becomes especially important to many families as they prepare to transition out of EI.

Parent's Rights

Parents of children in EI have certain rights that are specified by state and federal laws. These rights are known as "procedural safeguards." Procedural safeguards are intended to encourage parent(s) to play an active role in the decision-making process regarding EI services, and to provide opportunities for the family to fully inform the EI team about their views and priorities. All families in EI receive the "Family Rights" booklet, which explains the procedural safeguards in detail.

Contact Information for Early Intervention Sites

EI providers are located at a number of sites throughout the state of Rhode Island. A family can choose the EI provider site listed that best meets the needs of its child and family. Sites include:

Children's Friend and Service
621 Dexter Street, Central Falls, RI 02863
Phone: (401) 721-9200
Fax: (401) 729-0010
Website: www.cfsri.org

Easter Seals

5 Woodruff Avenue, Narragansett, RI 02882

Phone: (401) 284-1000

Fax: (401) 284-1006

Website: www.eastersealsri.com

Family Resource Community Action

245 Main Street, Woonsocket, RI 02895

Phone: (401) 766-0900

Fax: (401) 766-8737

Website: www.famresri.org (look under “How We Can Help”)

Family Service

134 Thurbers Avenue, Providence, RI 02905

Phone: (401) 331-1350

Fax: (401) 277-3388

Website: www.familyserviceri.org

Hasbro Children’s Hospital

593 Eddy Street, Providence, RI 02903

Phone: (401) 444-3201

Fax: (401) 444-6115

Website: www.lifespan.org/partners/hch

J. Arthur Trudeau Memorial Center

Kent County Chapter ARC

250 Commonwealth Avenue, Warwick, RI 02886

Phone: (401) 823-1731

Fax: (401) 823-1849

Website: www.kentcountyar.org

J. Arthur Trudeau Memorial Center

South County Early Intervention Program

140 Point Judith Road, Unit 44, Narragansett, RI 02882

Phone: (401) 783-6853

Fax: (401) 783-6846

Website: www.kentcountyar.org

James L. Maher Center
120 Hillside Avenue, Newport, RI 02840
Phone: (401) 848-2660
Fax: (401) 847-9459
Website: www.mahercenter.org

Meeting Street Center
667 Waterman Avenue, East Providence, RI 02914
Phone: (401) 438-9500
TTY: (401) 438-3690
Fax: (401) 431-6639
Website: www.meetingstreet.org/matriarch

The Groden Early Intervention Center

If your child has symptoms of autism or a diagnosis of an ASD, the EI site you select may refer your child to Groden EI. The Groden Center, Inc., founded in 1976, is a non-profit agency that serves individuals with ASDs of all ages. The Groden Center EI program is the only EI site in Rhode Island that is designed to work specifically with children with ASDs. The Groden Center does not provide families and children with full services, but works with an EI full-service provider to coordinate all needed services.

TRANSITION FROM EARLY INTERVENTION

All EI providers have adopted procedures to ensure a smooth transition for children from EI to Local Education Agency (LEA) and/or appropriate community services and supports. This process begins with an overview of transition when the child is determined eligible for EI services. Parent education and parent-to-parent support is provided regarding the general transition process when the child is enrolled in EI. At 24 months, each family must be given a copy of “Transition from Early Intervention: A Family Guide.”

When the child is 28 months old, a certified EI provider is required to notify the Local Education Authority (LEA). Parental consent for referral to other community services and supports is requested by the service coordinator and once received is sent to the appropriate agencies.

Additionally, ALL Medicaid eligible children, with parental consent, must be referred to a CEDARR Family Center at 30 months of age.

Parents will be informed that eligibility for EI and for special education are different and that not all children receiving EI services are eligible for preschool special education services.

However, since eligibility for special education is not yet known and since all families should be connected to appropriate community services and supports, a transition-planning meeting will be held for all families. It is the responsibility of EI providers to help families access all available resources and to establish a transition plan including steps to exit from the system, regardless of whether or not a child is eligible for preschool special education services.

In summary:

1. At 28 months, a referral is made to the Local Education Agency (LEA) and appropriate community services and supports.
2. At 30 months, EI provider service coordinator will schedule and convene the transition planning meeting with appropriate transition team members.
3. Between 30–36 months, the LEA holds an eligibility meeting.
4. Between 30–36 months, if the child is eligible for special education, the IEP meeting is convened.
5. Between 30–36 months, if the child is not eligible for special education, the EI provider service coordinator and transition planning team members refer the family to appropriate community services and supports.
6. Between 30–36 months, ALL Medicaid eligible children must be referred to a CEDARR Family Center, given parental consent.

CEDARR FAMILY CENTERS

CEDARR Family Centers (CFCs) provide families of children with special health care needs with information, clinical expertise, connection to community supports, and assistance to help them meet the needs of their child. Children can be referred to CEDARR by parent(s) or guardians, physicians, EI programs, schools, community agencies, and other service providers.

CEDARR Family Centers provide services in coordination with other programs in which children may be participating. The services available through the CEDARR Family Centers include: basic services and supports, specialized clinical evaluation, family care plan development, crisis intervention services, and family care coordination assistance. CEDARR Family Centers can make referrals for services and can coordinate CEDARR direct services indicated on the family care plan. CEDARR direct services are Home-Based Therapeutic Services (HBTS), Personal Assistance Services and Supports (PASS), and Kids Connect (formally known as Therapeutic Child and Youth Care). For more information on direct services, refer to Section 6 of this guide. Enhanced services have been developed to broaden the services offered to children and families by the CEDARR Family Centers.

For more information about CEDARR Family Centers, visit the Rhode Island Department of Human Services website at www.dhs.ri.gov or contact the Rhode Island Department of Human Services at (401) 462-5300. There are, currently, four CEDARR Family Centers in Rhode Island and each serves families statewide. Families can choose the CEDARR Family Center that best meets the needs of their child and family.

About Families, CEDARR Family Center

203 Concord Street, Suite 335, Pawtucket, RI 02860

Phone: (401) 365-6855

Fax: (401) 365-6860

Website: www.aboutfamilies.org

About Families Satellite 1

1 Cumberland Street, 4th Floor, Woonsocket, RI 02895

Phone: (401) 671-6533

Fax: (401) 671-6532

About Families Satellite 2

1 Frank Coelho Drive, Portsmouth, RI 02871

Phone: (401) 683-3570

Empowered Families CEDARR Family Center

82 Pond Street, Pawtucket, RI 02860

Phone: (401) 365-6103 or (888) 881-6380

Fax: (401) 365-6123

www.empoweredfamilies.org

Families First CEDARR Center

Hasbro Children's Hospital, Room 120

593 Eddy Street, Providence, RI 02903

Phone: (401) 444-7703

Fax: (401) 444-6115

Solutions CEDARR Center

134 Thurbers Avenue, Suite 102, Providence, RI 02905

Phone: (401) 461-4351 or (800) 640-7283

Fax: (401) 461-4953

Website: www.solutionscedarr.org

Solutions Satellite

Lafayette Mills, 610 Ten Rod Road, Unit 13, North Kingstown, RI 02852

Phone: (401) 294-6138

Fax: (401) 277-3373

OTHER RESOURCES

As you research treatments, education, and medical services for your child with an ASD, you may find yourself needing other services and support. You don't have to face your child's ASD alone. There are many community resources available in Rhode Island for children with ASDs and their families. Section 6 of this manual contains an extensive list of the programs and resources in Rhode Island that are dedicated to providing services for children with ASDs, including:

- » Education
- » Evaluation, Assessment and Diagnosis
- » Legal Assistance/Advocacy
- » Service coordination/resource centers
- » Support for Parents and Families
- » Therapeutic Recreation
- » Transportation Services
- » Treatment and Therapeutic Services
- » Vocational Assistance/Transitional Services

Individual, Exceptional, and Unique

Following is Leigh Ann's story, a mother of twin girls with ASDs.

I remember the day distinctly. It was a Tuesday morning, April 2004, when I met with my Early Intervention team. My twin daughters were two years and seven months old. My daughters had done poorly on their tests the week before, and I had to know how delayed they were in their skills. Being that they were preemies, born at 32 weeks, I knew that my daughters would be a little behind on things. They didn't smile when the books said they would; they didn't roll over, stand, sit or even walk when they should have. These girls weren't saying any words, they had no comprehension, and boy, did they move around an awful lot. Twins are known to have some developmental delays, and then they grow out of it. The evaluations had been scored, and in my mind, the evaluations had to be definitely in our favor because, after all, they are preemies and they will catch up.



When I heard the word “Autism,” it scared me. It angered me. I had no idea what to say or how to react. Here I had this team of professionals, who I had invited into my home once a week for two and a half years, tell me that my daughters have traits of a neurological disorder called Autism. All I knew was “Rain Man.” I thought, “Oh my God, are my kids going to be like Rain Man?” In that instant, my dreams for my daughters were gone. Goals I had for them – gone. The hopes of them having lots of friends and slumber parties – gone. Marriage, children, LIFE – GONE! As my service coordinator, physical therapist and occupational therapist tried so gently to educate me in ‘Autism 101,’ I found my heart grieving, my knees buckling, my mind wandering, and my tears just waiting until I was all alone.

My daughters just turned four years old in September 2005. I can’t tell you the improvements that I have seen in them. Are they still behind developmentally? Yes. But guess what? They smile, and they roll over (yes they’ve graduated to doing flips now, thanks to their older brother, whom they love to imitate). These girls are full-time in a public school setting learning how to interact, communicate, reason, and take care of themselves.

My journey thus far has been the hardest undertaking I have ever had in my life. Decisions that can only be made by a loving, protective mom were at times too much for me to bear. Although I am married to a supportive and loving man, I found that even as a father, he couldn’t share in the heart-wrenching moments I found myself in so frequently. I can tell you this for sure, I know that my daughters have a plan and a purpose for their lives. It’s a plan for them not to fail, but to succeed. This is a plan that will teach them to grow and to be fulfilled as the individuals they were created to be. In this I have put my trust, in knowing that all that I’ve learned, all that I’ve been through, and all that I will continue to go through, will be for a purpose.

I have educated myself. With the help of organizations like the Rhode Island Parent Information Network, the Autism Project of Rhode Island, and CEDARR, I have found empowerment in obtaining information that will increase my knowledge of Autism and educational options for my girls. My daughters are learning a different way than the typical child does. Does that make them inferior? No. It makes them individual, exceptional, and unique, as now my dreams are for them.

Treatment and Interventions

“What makes the difference between wishing and realizing our wishes? Lots of things, of course, but the main one, I think, is whether we link our wishes to our work. It may take months or years, but is far more likely to happen when we care so much that we’ll work as hard as we can to make it happen. And when we’re working toward the realization of our wishes, some of our greatest strengths come from the encouragement of people who care about us.” *The World According to Mister Rogers*

SELECTING A TREATMENT

There are over 400 different treatments and interventions for ASDs which work to different degrees based on the child. It is important to match a treatment or intervention with the needs and strengths of your child. No one treatment works for all children with an ASD. Factors to consider when choosing treatments and interventions include: your child’s age, level of ability (mild, moderate or severe autism), type of learner (visual/seeing or auditory/hearing), behaviors and previous treatments. Before deciding on a treatment for your child, learn about the different options and discuss them with your child’s doctor, specialists, and with other parents of children with ASDs. Remember, however, while professionals and others can provide you with advice, ultimately, you are the decision maker.

Some suggested questions you can ask to help find the best treatment approach for your child include:

- » Has the treatment been recognized by researchers in the field of ASDs?
- » How has the treatment worked for other children?
- » Will the treatment harm my child?
- » Will the therapy fit into our family routine?
- » What are the qualifications of the therapist?
- » Can the treatment be integrated into other educational programs?
- » What therapies can be used in combination with each other?

- » Is there published scientific support for the treatment (that is, tests or proof of the treatment's effectiveness in medical or educational journals)?
- » What are the financial costs? Is the therapy covered under insurance or Medicaid or is it paid out-of-pocket?

Many treatments have been developed to address a range of social, language, sensory, and behavioral challenges that children with ASDs may show. Different treatments work better for a child at different stages of development. Brief descriptions of some of the better-known treatments are provided below. The treatments and interventions are separated into three categories:

- » Behavioral approaches
- » Biomedical and dietary approaches
- » Medications

Please note that the Rhode Island Department of Health does not endorse or promote any method, treatment, specific medication, or dietary intervention. This information is provided only as part of an overview of the treatment options available. Families should talk to a doctor for advice and more information.

BEHAVIORAL APPROACHES

APPLIED BEHAVIORAL ANALYSIS (ABA)

Applied Behavior Analysis (ABA) is one of the only interventions that has proven results for people with ASDs. It is based on the theory that all learned behaviors have an antecedent (what happened before the behavior) and a consequence (what happened after the behavior). This means that people are motivated by positive or negative consequences to repeat or not to repeat a behavior. In this treatment, a skill is broken down into small steps and taught in a one-on-one teaching session. The child is given repeated learning opportunities with clear, simple cues, and immediate and consistent rewards for correct responses. Skills are also practiced outside of the classroom in environments such as the home and community settings (e.g., park, store, restaurant). Negative behaviors (tantrums and aggression) are not rewarded. Instead, more appropriate behaviors are taught in their place. Parent(s) can research Applied Behavior Analysis Programs to ensure that providers are certified by accessing the following website: (www.bacb.com) or FEAT–Families for Effective Autism Treatment (www.featri.org).

AUDITORY INTEGRATION THERAPY

This method of treatment is based on the theory that some children are very sensitive to certain sounds, making them painful to hear. Auditory integration therapy reduces over-sensitivity to

sound. It may involve having the child wear headphones to listen to a variety of sound frequencies and music. This treatment is done over a period of time. The effectiveness of this method has not been proven. For more information, visit the website, www.sait.org.

FLOOR TIME

Floor Time (or Greenspan Floor Time) encourages the child to interact through play. The four goals of Floor Time include: encouraging attention and affection, fostering communication, encouraging the use of ideas and feelings, and logical thinking. This method focuses on the emotional growth of the child and can be used in conjunction with other therapies and treatments. For more information, visit the website, www.stanleygreenspan.com.

OCCUPATIONAL THERAPY

Occupational therapy may help children with ASDs to develop appropriate social, play, and learning skills. The occupational therapist helps the child in performing daily tasks such as getting dressed, appropriately responding to information coming through the senses, and interacting and communicating with others. As children grow, occupational therapy gives them the skills needed to lead independent and satisfying lives. For more information, visit the website, www.wfot.org.

PHYSICAL THERAPY

Pediatric physical therapists diagnose and treat infants, children and adolescents with a variety of disorders/diseases. Treatments focus on improving gross and fine motor skills, balance and coordination, strength and endurance as well as cognitive and sensory processing/integration. Physical therapists work on building the child's strength and endurance through physical and strength-building exercises. For more information, visit the website, www.fsbpt.org.

PICTURE EXCHANGE COMMUNICATION SYSTEMS (PECS)

The Picture Exchange Communication System (PECS) allows a child to communicate using pictures or a series of pictures to form a sentence. The goals of picture exchange are for a non-speaking child to develop communication skills and to interact with others. PECS requires the child handing the parent or therapist a picture (icon or symbol) of something he or she wants. Basic concepts such as numbers, colors, shapes and reading can be taught by using this method. PECS does not require expensive materials and it can be easily incorporated into any existing program. For more information, visit the website, www.pecs.com.

PICTURE REHEARSAL

Picture rehearsal is a method that uses sequenced pictures and a script which depict when, where and how to use a specific sequence of behaviors. The scenes are written using a positive reinforcement framework and have three components: the antecedents (A); the behavior to increase (B); and the consequence (C). The goal of Picture Rehearsal is to teach the child ways to control his/her responses to stressful situations. It combines a proven behavioral approach to learning (A-B-C) with the visual supports that are both necessary and effective in assisting a child with an ASD to learn. For more information, visit the website, www.grodencenter.org.

RELAXATION THERAPY

Relaxation therapy involves learning how to change a tense body state to a relaxed one, thereby reducing stress. The child learns to tell the difference between muscles that are tense and muscles that are relaxed. This is taught in a structured way, beginning with readiness skills, moving to sequentially tightening and relaxing larger muscle groups, and adding breathing exercises. When through daily practice, the child responds to relaxation prompts, the child is taught when to use this skill. The method aims to help the child identify both bodily signs of stress and situations that may cause those signs. For more information, visit the website, www.grodencenter.org.

SENSORY INTEGRATION

Children with ASDs are often over- or under-sensitive or may lack the ability to integrate their senses. Sensory integration therapy, usually done by an occupational therapist, focuses on desensitizing or retraining the senses (smell, taste, sight, touch or hearing). For example, if a child has difficulties with the sense of touch, therapy might include handling a variety of materials with different textures. Opportunities for sensory integration therapy can be worked into the child's daily routine in the home, school, or other community settings. Many children with ASDs need to incorporate sensory activities throughout their day. These activities are developed by the therapist and tailored to each child's needs in a plan called a Sensory Diet. A sample Sensory Diet is provided on the next page. For more information, visit the website, www.sensoryint.com.

Sample Sensory Diet

PURPOSE:

- » To stimulate the child's senses throughout the day in order to keep him or her focused.
 - » To use sensory activities to help a child stay calm and focused.
-

MOVEMENT (VESTIBULAR SYSTEM) AND MUSCLE (PROPRIOCEPTIVE SYSTEM)

Procedure: Use movement of the muscles, joints, and eyes to remain focused and attentive to task.

Movement that Creates Calming Effect

- » Swinging – rhythmically – calming
- » Slow rocking over ball or bolster

Movement that Creates Alerting Effect

- » Jumping on trampoline
- » Scooter board – pulled by adult: child pulls on hoola hoop to speed up
- » Scooter board – push or pull self using hands (lying prone) or feet (sitting)
- » Hanging from bar
- » Climbing ladder
- » Swinging with irregular movement – stops/starts, bumps

Movement that Creates Organizing and Calming Effects

- » Weighted vest worn while walking, moving
- » Wrist or ankle weights worn while walking, moving

Deep Pressure that Creates Organizing and Calming Effects

- » Rolling a therapy ball or paint roller with pressure on the back & limbs
- » Theraputty
- » Wearing weighted shoulder pad, weighted lap pad or blanket
- » Wearing a pressure vest
- » Vibration
- » Foot squeeze, upper chest squeeze, shoulder pushes
- » Arm/hand massage, finger pulls

**ORAL SENSORY SYSTEM (AUDITORY/HEARING, OLFACTORY/SMELLING,
GUSTATORY/TASTING SYSTEMS)**

Procedure: Use muscle, oral and smell stimulation to remain focused and attentive to task.

Activities that Create a Calming/Organizing Effect

- » Eating Crunchy Foods
- » Eating Chewy Foods
- » Sucking Thick Liquids (milkshakes)

Activities that Create an Alert Effect

- » Eating Sour Foods
- » Eating Spicy Foods

Activities that Create a Calming Effect

- » Relaxation
- » Playing music nearby
or with a headset
- » Wearing headset with no music –
to block noise (for defensiveness)



SOCIAL COMMUNICATION, EMOTIONAL REGULATION AND TRANSACTIONAL SUPPORTS MODEL

The SCERTS™ Model is a comprehensive, multidisciplinary approach to improving communication and social/emotional abilities by addressing the core challenges faced by children with ASDs and related social-communicative disabilities and their families.

It is based on the belief that children do best when there is an educational focus on:

1) communicating with others and developing relationships (Social Communication);
2) enhancing the ability to stay in a well-regulated state for learning and interacting (Emotional Regulation); and 3) supporting children and parents in various ways (Transactional Support). The SCERTS™ model focuses on functional skills in every day activities across settings and is based on the unique learning style of children with ASDs. It is not an exclusive approach; it provides a framework in which practices from other approaches may be integrated. Assessment occurs through observation of children in different settings and with different partners using a detailed curriculum-based assessment and parent report. It can be used with a wide range of developmental abilities, including both preverbal and verbal children. It is also relevant for older school-age children and adults. Particular emphasis is given to parent-professional collaboration. For more information, visit the website, www.SCERTS.com.

SOCIAL STORIES

Social stories were developed as a tool for teaching social skills to children with ASDs. Through a story developed about a particular situation or event, the child is given information to help him or her understand the expected or appropriate response. The stories can be written by anyone, are specific to the child's needs, and are written in the first person, present tense. They frequently use pictures, photographs, or music based on the child's abilities and interests. Before developing and using a social story, it is important to identify how the child interacts socially and to determine which situations are difficult and what makes them difficult. Situations that are frightening, produce tantrums or crying, or make a child withdraw or want to escape are examples of where a social story could help. Only one problem should be addressed in a social story at a time. The most important element of a social story is to keep it positive 100% of the time. For more information, visit the website, www.thegraycenter.org.

SPEECH & LANGUAGE THERAPY

Speech and language therapy begins with a complete evaluation of the child's ability to communicate. No single treatment has been found to improve communication in all individuals who have ASDs. Once a diagnosis is made, speech therapy should begin as soon as possible. Speech therapy should be tailored to the child, should target both behavior and

communication, and should involve parents or primary caregivers. The goal of therapy should be to improve useful, functional and social communication. There are many treatments available based upon a child's strengths and needs. Treatment should include periodic evaluations by a speech-language pathologist. Occupational and physical therapists may also get the child ready to learn when working on language development. For more information, visit the website, www.asha.org.

TREATMENT AND EDUCATION OF AUTISTIC AND RELATED COMMUNICATION HANDICAPPED CHILDREN (TEACCH)

TEACCH is an internationally recognized structured teaching approach based on the idea that the environment should be adapted to the child with an ASD, not the child to the environment. Organizing the physical environment, developing schedules and work systems, making expectations clear, and using visual materials have been effective ways of developing skills and allowing children with ASDs to use these skills independently. Rather than teaching a specific skill or behavior, the TEACCH approach aims to provide the child with the skills to understand his/her world and other people's behaviors. Communication skills, social skills, inclusion and curriculum are all designed to meet the child at his/her current level of functioning and to take that child as far as he/she can go. For more information, visit the website, www.teacch.com

ADDITIONAL THERAPIES

- » Art therapy gives tactile (feeling, touch), visual, and auditory (hearing) stimulation. It can provide a nonverbal way for a child with an ASD to communicate and express himself or herself.
- » Music therapy is used for speech development and language comprehension. Songs teach language and help children put words together.
- » In HIPPO Therapy, children use horseback riding to increase muscle tone and sensorimotor response (integration of sensory and motor aspects of bodily activity).

BIOMEDICAL AND DIETARY APPROACHES

ANTI-YEAST (OR ANTIFUNGAL) DIET

A diet sometimes used in the treatment of children with ASDs is the Anti-Yeast Diet. Advocates of this diet say that children with ASDs may have a “leaky gut” – tiny holes in their intestinal tract that may be caused by an overgrowth of yeast, which may be contributing to their behavior and/or medical problems. The Anti-Yeast Diet removes yeast from the diet and/or uses nutritional supplements and anti-fungal drugs. It is important to talk to a doctor before trying this diet. For more information about the Anti-Yeast Diet, visit the Autism Network for Dietary Intervention website at www.autismndi.com.

GLUTEN FREE/CASEIN FREE DIET

Some children with ASDs may have allergies to certain foods or chemicals. Advocates of the Gluten Free/Casein Free Diet say that these food intolerances or allergies may contribute to behavioral issues that are associated with ASDs. The theory is that the child’s digestive system cannot break down peptides from foods that contain gluten and casein, impacting the child’s brain function and ability to process information. Casein is found in dairy products and gluten is found in wheat, oats, and rye. The Gluten Free/Casein Free (GFCF) Diet removes all products that contain gluten and casein from the diet to monitor any resulting positive changes in behavior. It is important to talk to a doctor before trying this diet. For more information, visit the Autism Network for Dietary Intervention website at www.autismndi.com.



SECRETIN (HORMONES)

Secretin is a hormone that is produced by the small intestines to help the body with the digestion process. Some people believe that giving children secretin improves some symptoms of an ASD, such as sleep patterns, eye contact, language skills and alertness. It is important to note that the Food and Drug Administration (FDA) only approves secretin in a single dose, and there are no studies that show it is safe to use. Additional information can be accessed through the Autism Research Institute website at www.autismresearchinstitute.com

VITAMINS AND MINERALS

Children with intestinal disorders and chronic intestinal inflammation may not absorb nutrients needed to maintain the immune system. Some children with an ASD may have low or high levels of vitamins and minerals. When considering the addition of vitamins and minerals to a child's diet, parents should talk to a doctor who is knowledgeable in nutritional therapy. A doctor can evaluate the child's nutritional status through a blood test or clinical assessment.

MEDICATIONS (PSYCHOPHARMACOLOGIC TREATMENTS)

There are many medications that were developed for other conditions but have been found effective in treating some of the symptoms and behaviors associated with ASDs. The goal of medications is to reduce these behaviors to allow the child with an ASD to take advantage of educational and behavioral treatments.

Parents should be clear about what they want to see improved through medication. Symptoms such as disrupted sleep or appetite, increased anxiety or increased aggressive behavior may be addressed through the use of medication. Although medication will not change a child's IQ or cure an ASD, medications can improve some symptoms and can allow a child to do better in school, to tolerate change, or to get along better with family members and peers. Some children, for reasons that are not well understood, simply do not do very well on medication.

QUESTIONS FOR THE DOCTOR

Following are some suggested questions that families should ask the doctor before beginning medications:

- » How safe is the drug?
- » What are the side effects of the drug?
- » Is there any research on the drug and its use in children with ASDs?
- » How is it given (pills or liquid)?
- » Are there possible interactions with other drugs, vitamins, or foods?
- » How will my child be monitored and by whom?

When medications are begun, there are some basic rules that should be followed:

- » Given the complexity of medications, drug interactions, and the unpredictability of how each patient may react to a particular drug, parents should seek out and work with a medical doctor with an expertise in the area of medication management.
- » Evaluations should include a thorough medical history.
- » Risks and benefits should be discussed.
- » Appropriate medications with the fewest side effects should be started first.
- » The lowest possible dose should be used at first to avoid adverse reactions.
- » Medications should be used long enough and in doses that will show if they work.
- » Objective data, such as rating scales or measuring discrete behaviors, should be used to assess efficacy. This is particularly important when many people weigh in on a medication trial.
- » Families should always be allowed to end a medication trial, unless doing so would harm the child. Families should be given clear instructions on how to stop a medication.
- » Medications should never be used for the convenience of parents, teachers or staff working with a child or adult with an ASD.
- » Regular monitoring is always necessary. If medications are not effective they should be changed or stopped.
- » At no time should the child be overly sedated, cognitively impaired, or unable to function.
- » Lastly, although medication might not have been effective in the past, it may be worth trying again in the future. Weight gain, growth and greater maturity may, at times, allow a medication that didn't work in the past to be more therapeutic.

Families can get more information about medications through the National Institute of Health website at www.nih.gov.

Matthew's Story

Following is Deb's story about her son Matthew, who has an ASD, and his struggles with education.

In March 1985, a beautiful, bouncing baby boy was born. In January 1987, he was diagnosed with autism, and his family's life changed forever. Matthew looked like the three B's of babies with autism: big, blonde, and blue-eyed. At least that's what many looked like in 1987. Back then, autism showed up in 1 out of 10,000 births, with 3 out of 4 being males. We were a bit of an oddity then, but things have certainly changed since.

It was a good three days before the diagnosis set in and the grief began. It was deep and nauseating, but eventually floated away like fog after a good rain. After all, he was still my Matthew. Could life really change that much? We found out soon just how much. When our school system wanted to label him with mental retardation after spending 15 minutes "observing" him, I knew that it would be up to my husband and I to advocate for the best care possible; nobody would be doing this for us.

We ended up in a pre-hearing conference with our school system and won the right to have him educated at the Groden Center in an integrated pre-school program. Back then, very few programs provided integration with typically developing children, but the few studies I had read and our gut told us that this would be extremely important for Matt's success. Placing him there when he was three was the first good decision we made, and sending him back to his home school in Coventry three years later was the second.

When he finally said "mom," he was five years old, and shortly after, he became toilet-trained, which were miracles in themselves. He left the Groden program toilet-trained, using some basic words, and able to read close to 200 sight words. I still keep the flash cards in my bed stand to remind me of where we've been. He entered Kindergarten with a trained one-on-one teaching assistant at Washington Oak School in Coventry. Little did I know that the wonderful peers he came to know as friends on that first day in September of 1991 would become the young adults with whom he would graduate from Coventry High School in June 2004.

I would love to say that the wonderful assistants and great peers he had over the years were enough to make everything perfect in school. But that would not be true. His autism, combined with a diagnosis of Bipolar Disorder at the age of nine, made his life and ours quite challenging. Now we had a child with mood swings who could not tell us how he felt. The

crying, the anger, the anxiety were all part of the everyday experience throughout his school years. The challenges to our school system as well as to our family, especially to his brother and sister, were on going. Just when we thought we had the right direction and supports, things would change again. There were days when his OCD was so bad that it would take him two hours just to get from his bedroom to the morning school bus. Many of those days, we just pulled down the shades and stayed home.

But the reality is that Matthew's autism has brought us joys greater than any sorrow we experienced. The friends, doctors and support we have been blessed with along the way are simply the best of the best. There have been "moments of greatness" I didn't believe we would ever have experienced: the duet he and I sang in a school cabaret with a standing ovation of 400 people, the wilderness field trip where he had to climb over a ten-foot wall with six friends under him helping him over the top, the many years he sang the Star Spangled Banner for an auditorium full of people, or when he read Green Eggs and Ham to Kindergarten kids when he was in 5th grade, are just a handful of examples. And most importantly, walking across the stage and receiving his high school diploma with 450 of his classmates was a moment that will be etched in our hearts forever.

At 20 years old, we are getting ready for his adult life to begin. I'm sure there will be more challenges ahead. But I've learned that life has challenges for all of us. Because of his autism, Matthew has brought to our lives a sense of compassion, sensitivity and empathy we may never have known. The world could use a few more compassionate people ... maybe that's what autism is really meant to do!

Special Education

The public schools are responsible for providing all children with a Free Appropriate Public Education (FAPE).

If a child has an ASD that is affecting his/her progress in the general curriculum (i.e., the same curriculum for non-disabled children); or if the disability affects participation in appropriate activities, a referral for special education services and supports can be made. School district personnel need to document attempted interventions before the referral process takes place.

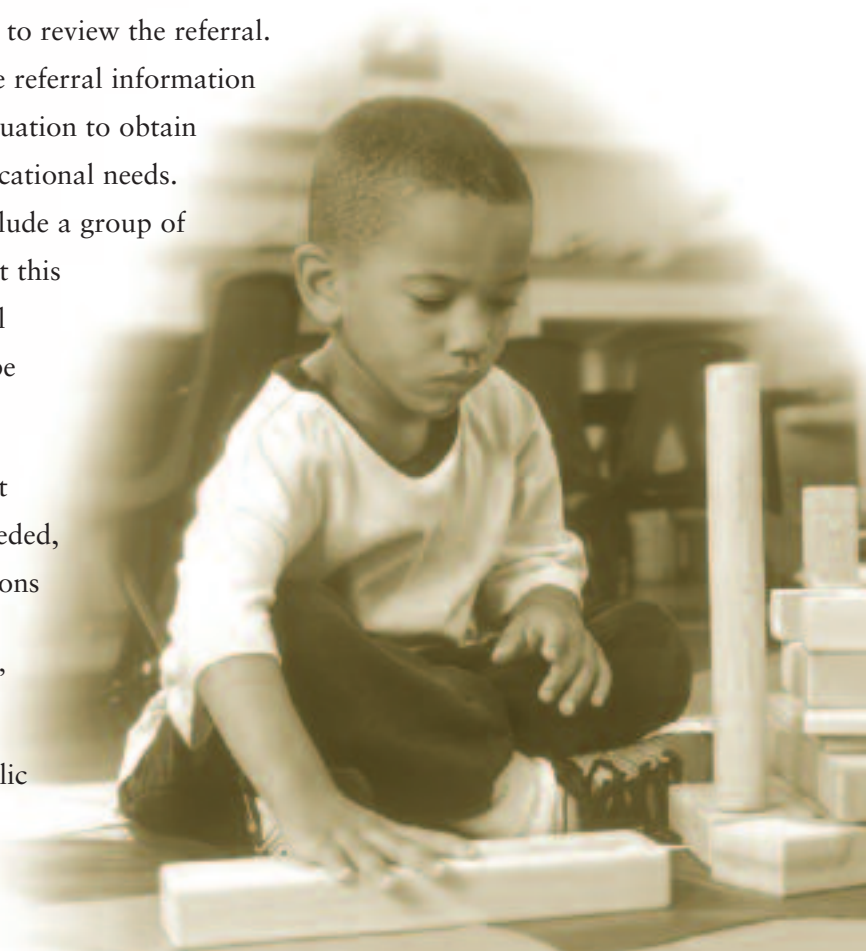
A referral is made to the special education department by a parent and/or teacher. If a child is currently enrolled in EI, the case manager can make the referral to the special education department.

Once a referral is made to the public school system, the school system has ten days upon the receipt of the referral to conduct a meeting to review the referral.

The purpose of the meeting is to review the referral information and to determine if a child requires an evaluation to obtain more information regarding the child's educational needs.

The participants of this meeting should include a group of qualified professionals and the parent. If, at this meeting, the team determines that an initial evaluation is not needed, the parent must be notified within ten school days.

If, at this meeting, the team determines that further information and evaluations are needed, the team would then decide which evaluations are necessary. The parents are given the opportunity to sign a "consent to evaluate" form, which gives the school department permission to evaluate their child. The public school system has ten days upon receipt of permission to begin the evaluation process.



SPECIAL EDUCATION EVALUATIONS

Various evaluations are required to help professionals better understand a child's abilities and needs. The following is a list of evaluations that may be required once the "Consent to Evaluate Form" has been signed. This list also includes, in parentheses, the professionals responsible for performing the evaluation.

- » Social History (School Social Worker)
- » Medical Evaluation (Child's Doctor)
- » Psychological Evaluation (School Psychologist)
- » Language and Communication Evaluation (Speech and Language Therapist)
- » Educational Evaluation (Diagnostic Prescription Teacher [DPT] or Special Education Teacher)
- » Sensory or Fine Motor Evaluation (Occupational Therapist)
- » Physical Development or Gross Motor Evaluation (Physical Therapist)
- » Adapted Physical Educational (APE) Evaluation (School's Adapted Physical Education Teacher or Physical Education Teacher)
- » Functional Behavioral Analysis (FBA) (School Psychologist, Teacher, or Team of Identified Individuals)

The school department has 45 school days to complete the evaluations.

Upon completion of the evaluations, the evaluation team will reconvene with the family to discuss the child's evaluation results and to determine if the child is eligible to receive special education services. Once a child with an ASD has been determined eligible for special education, he/she is eligible under the category of Autism. This includes:

- » Autism
- » Asperger Disorder
- » Childhood Disintegrative Disorder
- » Pervasive Developmental Disorder
- » Rett's Disorder

INDIVIDUALIZED EDUCATION PLAN (IEP)

The Individualized Education Plan (IEP) is the document that serves as a written agreement between the student's parent and the school system. Following the evaluations, a meeting is held to develop an IEP for the child. All teachers and professionals who will be involved in educating the child should be invited to the IEP meeting. Families also have the right to invite other individuals whom they feel necessary to include to the IEP meeting, such as the child's

occupational therapist, speech and language therapist, physical therapist, social worker, or home-based therapy agency representative. A packet containing information about parents' rights under the law, called "Procedural Safeguards," should be handed to or offered to families at every meeting.

The opening of the meeting should include introductions of all participants. It is important that parents have a clear understanding of who is at the meeting and what their role is in the development of the child's program.

At the IEP meeting, the student's current abilities and strengths are discussed, along with his/her developmental and educational needs. Short- and long-term goals are decided upon, and educational options are discussed. The following are the various options that will be considered by the team during the IEP meeting:

- » Regular education classroom with consultation from special education.
- » Part-time placement in a regular education classroom, with supplementary part-time placement for a portion of the school day or of the school week in a separate area set aside for intensive, individual, small group instruction.
- » Placement in special education classes for less than 50% of the student's day.
- » Part time placement in a regular education classroom, with supplementary part-time placement in a self-contained classroom (if a child is in a special education classroom for more than 50% of his/her school day, it is considered a self-contained placement, even though the classroom may not be referred to as a self-contained placement).
- » Full time placement in a self-contained special education classroom.
- » Home or hospital instruction.
- » Special day school.
- » Special education residential placement.

The Individuals with Disabilities Education Act (IDEA) presumes that the first placement option considered for each student with a disability is the school that the child would attend if he or she were not disabled, with appropriate aids and services to facilitate such placement. If a determination is made that the student cannot be educated satisfactorily in the regular education environment, even with additional aids and services, the student may then be placed in a setting other than the regular education classroom (see Alternative Placement section on page 63).

Placement decisions must be determined on the basis of each student's abilities and needs, and not solely on factors such as category of disability, significance of disability, availability of special education and related services, availability of the space and administrative convenience.

IEP meetings are held one time per year. If needed (e.g., the student's needs are not being met), the parents and educators have the right to call an IEP meeting prior to the date of the yearly meeting. For more information on writing the IEP, visit the Rhode Island Technical Assistance Project website at www.ritap.org and click on the Rhode Island IEP Network.

The following is a list of tips created by families to help make sure that your IEP meeting is a positive experience.

- » Bring a friend or family member to the meeting with you.
- » Go to the meeting prepared. Bring information about your child's strengths and needs using examples from what you see at home or in other settings.
- » Carry written information in a folder or notebook.
- » Shake hands and acknowledge other people at the meeting. Sit with the team. Remember, you are part of the decision-making process.
- » Ask questions and ask for clarification of anything that you do not understand.
- » Focus on the issues at hand. Do not be sidetracked by other issues, such as past experiences.
- » Remain as friendly as possible. Keep your emotions in control.
- » Make your proposal and expect to get what your child needs. Be flexible enough to accept minor revisions, but be firm on major issues.
- » Feel confident to end the meeting if it seems that no more progress can be made. Tell the other team members that you would like to continue working with them, and set up another appointment for a fresh start.
- » Remember, you are advocating for the safety, health and well-being, and future of your child. If you do not do it, who will?



504 PLAN

A 504 Plan is a plan for a student with a disability who does not meet the eligibility for special education services but has a medical condition that may require modifications to his/her educational program. This plan is written with a team of general education professionals and the family and is intended to prevent discrimination of the child with the disability.

ALTERNATIVE PLACEMENTS

If a determination is made by the IEP team that the student cannot be educated satisfactorily in the regular education environment, even with additional aids and services, the student may be placed in a setting other than the regular education classroom. This is called an out-of-district placement.

Once an appropriate private school or facility is identified, the IEP team makes a referral to that facility. It is important for the team to recognize that out-of-district placements depend on the availability of spaces. There are times when the placement of choice is full, and the team will need to reconsider another placement option. It is important to “match” the student’s needs with the type of programming that a private school or facility offers to ensure that the placement will help the student make progress.

IEP teams also make the decision regarding the amount of time that the student participates in an out-of-district placement. For some students, the IEP team could choose a short-term, or interim, private placement (e.g., a 45-day interim private school placement option). A short-term or interim option is sometimes needed to allow a student to receive a comprehensive evaluation that the district cannot provide. A comprehensive evaluation provides the IEP team with information that is relevant to the student’s functioning and programming needs.

Other students may require a long-term placement in an out-of-district school or facility to support their learning needs. The time frame and decision regarding this placement is made and annually reviewed by the IEP team.

See the Community Resources and Websites section for a list of alternative placements in Rhode Island.

Based on 2001 recommendations by the National Research Council on Educating Children with Autism, the educational goals for students with ASDs are the same as those for other children (e.g., independence and social responsibility). These goals imply progress in social and cognitive abilities, verbal and nonverbal communication skills, and ability to adapt in different situations (e.g., can perform skills at home or school); reduction in behavioral difficulties; and generalization of abilities across environments.

Students with ASDs benefit from programming geared to the core deficits of the disorder. Joint attention (showing or pointing to direct attention) and symbol use (understanding the meaning of words and gestures, using objects functionally and in symbolic play) are two of the core ASD communication deficits that must be addressed.

In 2001, the National Research Council published its recommendations regarding interventions for children with ASDs up to eight years of age. Some common characteristics of an appropriate education program are:

- » **Intervene as early as possible.** There are windows of opportunity for involvement, which are lost without early intervention.
- » **Intensity matters.** Early intervention, preschool, and education services should be engaging, intense and consistently provided. This level of engagement is needed to counter withdrawal and to further a child's progress at key stages of early brain development.
- » **Plan developmentally-appropriate educational activities.** The child should be engaged in one-to-one or small group settings to achieve specific objectives.
- » **Priority interventions.** The priority interventions are to teach functional and spontaneous communication, social instruction in various settings, play skills with peers and toys, instruction leading to generalization of cognitive goals, positive approaches to problem behaviors, functional academic skills.
- » **Opportunities for interaction with typically-developing children.** Instructional settings should maximize opportunities to interact with typically-developing children.
- » **Professionals with specialized training.** Professionals require ongoing, specialized training due to the unique features of ASDs.
- » **Family information and education.** Families need information and education to participate in their child's education and to assist in generalizing skills and behaviors.

SIX INTERVENTIONS THAT SHOULD BE PRIORITIZED FOR CHILDREN WITH ASDs INCLUDE:

- 1) Teaching of functional and spontaneous communication.
- 2) Social instruction in various settings.
- 3) Play skills with peers and toys.
- 4) Instruction leading to generalization of cognitive goals.
- 5) Positive approaches to problem behaviors.
- 6) Functional academic skills.

ADVOCATING FOR YOUR CHILD'S SUCCESS IN SCHOOL

It is important for you to remember that your child can be as successful as any other child in school. The educational system is designed to provide as many supports as needed to assist all children in reaching their education goals. This is done through individualized programs tailored to meet each student's needs.

TRANSITIONING FROM ADOLESCENCE TO ADULTHOOD

Adolescence is a time of stress and confusion—and it is no less so for teenagers with ASDs. Like all children, they need help with their sexuality and the changes in their bodies. While some behaviors improve during the teenage years, some get worse. Increased aggressive behavior may be one way some teens express their new-found tension and confusion.



The School Years

The following story is written by Nancy, the mother of Cory, who has an ASD. Nancy's story picks up with her son's journey through the school ages.

When my only son was diagnosed with an ASD, I spent the first six months in denial. I then realized that I needed to give up the career that I loved and devote myself to helping my child. I immediately began to seek out the interventions I could find for my son. Lucky for us, I researched a methodology entitled ABA (Applied Behavior Analysis), a data-based approach to developing skills and addressing the needs of individuals with ASD. Basically this is an intensive program which teaches everything a child needs to learn by breaking it down into the smallest possible increments and presenting it to the child through repetitive trials utilizing lots of positive reinforcement. From the age of 3 to 5, my son received 35 plus hours a week of ABA. The progress he made was nothing shy of miraculous. I felt like I was getting my child back.

It was my goal to get my child prepared to enter kindergarten with his typically-developing peers. Because Cory had made such extraordinary progress in his ABA program, I had every reason to believe that this was an achievable goal. Cory entered a typical kindergarten with support. He had a daily regimen of school in the morning and therapy in the afternoon and was still making substantial progress. To make the transition to a full day in first grade, it was decided to put Cory in a self-contained classroom with the end result of transitioning him into full inclusion by the end of the first grade. He was so successful that he was fully mainstreamed by March of that year. The key to his success was having a trained teaching assistant work with him and a special educator to oversee his IEP.

We followed this model for 1st and 2nd grade. The biggest hurdle we faced was Cory's attention deficit emanating from his ASD. Once he hit 3rd grade and the school work became more demanding, things began to unravel for Cory. I began to realize just how severe his reading comprehension deficit was. It became apparent that for Cory to succeed, he would need a great deal of modifications made to the curriculum, tests, class work, etc. I knew that I had to form a partnership with Cory's resource teachers and regular education teachers. I had to work very hard advocating for Cory to ensure that he had the necessary modifications he needed in order to be successful in the regular education placement. It took many IEP meetings and a lot of perseverance to finally get an IEP that would appropriately address his needs.

Today Cory is a teenager who attends the neighborhood public school and is fully included with the support of a trained teaching assistant. He has maintained excellent grades in school and we are extremely proud of him. He goes to school dances, sings in the chorus, and is a very talented piano player. Cory also goes fairly regularly to the YMCA Teen Center and enjoys playing video games and pool with his peers. He is an avid Red Sox fan and is totally addicted to American Idol. Cory still receives HBTS services, where we are working on improving his social skills and instilling a better understanding of perspective taking.

It has been an arduous process to keep Cory in a regular education placement. I spend a lot of time using the ABA method to help him with his homework—breaking things down to the smallest pieces and using repetition and constant positive reinforcement. This is the learning style that works best for him. Is it hard work? Yes. Have we had our fair share of homework wars? Yes. Would I do this all over again? Absolutely. It has been a long, hard journey, but so worth it! I can honestly say that the utilization of ABA has made my son Cory what he is today, and I can see a bright future ahead for him.



The teenage years are also a time when children become more socially aware. At the age when most teenagers are concerned with acne, grades, popularity and dates, teens with ASDs may become very aware that they are different from their peers. They may notice that they do not have friends. And unlike their peers, they may not be interested in dating or driving a car. For some children, the disappointment of learning that they are different motivates them to learn new positive behaviors and social skills.

As children with ASDs move through adolescence into early adulthood, they will need an IEP Transition Plan. Transition planning begins at age 14 and is part of the IEP every year after that. At age 16, the IEP should plan how to help the young adult transition from school into the community. The goal is for the young adult with ASDs to become as independent as possible. Adolescents with ASDs should take part in the planning themselves because their input will help make the plan more successful. RI offers the services of Regional Transition Centers to assist youth and families with this process.

The RI Regional Transition Centers provide information, training and technical assistance to teachers, administrators and families of students in special education, ages 14-21, who are preparing for the transition from school to adult life. (See Community Resources and Websites Section for a list of Regional Centers.)

LIVING AND WORKING AS AN ADULT

HOUSING

Depending on the level of functioning, adults with ASDs have many choices as to their living arrangements. The following list describes the many different placements available for adults with ASDs.

Independent Living

Some adults with ASDs are able to live entirely on their own. Others can live semi-independently in their own homes or apartments if they have assistance with solving major problems, such as personal finances or dealing with government agencies that provide services to people with disabilities. A family member or professional agency can provide this assistance.

Living at Home

Government funds are available for families that choose to have their adult with an ASD live at home. These programs include Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid waivers, and others. It is necessary to make an appointment with your local SSI agency to understand what the adult is entitled to. For a complete list of SSI offices in Rhode Island, please visit the Community Resource and Websites section of this guide.

Foster Homes and Skill-Development Homes

Some families open their homes to provide long-term care to unrelated adults with disabilities. If the home teaches self-care and housekeeping skills and arranges leisure activities, it is called a “skill-development” home.

Supervised Group Living

Adults with ASDs often live in group homes or apartments staffed by professionals who help the individuals with their basic needs. Higher functioning adults may be able to live in a home or apartment where staff only visits a few times a week. In this type of living arrangement, adults are able to prepare their own meals, go to work, and conduct daily activities on their own.

Long-Term Care Facilities

Although the trend in recent decades has been to avoid placing individuals with ASDs into long-term-care facilities, this alternative is still available for people with ASDs who need intensive, constant supervision. Unlike the institutions of years ago, today’s facilities view residents as individuals with human needs and offer opportunities for recreation and simple but meaningful work.

WORKING

Some adults with ASDs, especially those with high-functioning ASDs or Asperger Disorder, are able to work successfully in mainstream jobs. Nevertheless, communication and social problems often cause difficulties in many areas of life. Adults with ASDs will continue to need moral support and encouragement in their struggle for an independent life.

Many other adults with ASDs are capable of employment in a workshop under the supervision of managers trained in working with people who have disabilities. A nurturing environment at home, school, and work allows the person with an ASD to continue to learn and develop throughout his or her life.

Ondrea's Story

Ondrea, a woman living with an ASD, provided her recollection of what it is like to live as an adult with an ASD.

Hi, everyone. My name is Ondrea, and I am 24 years old. I am the Residential Services Secretary for an agency in Rhode Island. I've been there since December 12, 2001, where I first started out as a receptionist. The reason I'm writing this is because I'm autistic. I was diagnosed at Bradley Hospital in East Providence with mild autism because my behavior wasn't normal. When I went to school in my younger days, temper tantrums started in the classroom, and I would get disciplined. In my later years, I would go to counseling to sort out my feelings about different issues.

But then again, I'm not your typical autistic person. It is said that a lot of autistic people do not make friends or socialize. I'm one of those exceptions because I like to meet people, and I do have some friends. I taught myself how to read and write when I was three years old. I did pretty well in school, especially in high school (I was in a regular education homeroom starting in the seventh grade, but I still went to Resource for assistance) and being on the honor roll every quarter. I ended up being on the National Honor Society, and I was one of the top twenty-three students in 1999.

Just because my grades were great didn't mean my socializations with some of my fellow classmates were! There were several of them who did not understand when they put me down. In the eleventh grade, I received detention for forging a teacher's signature on a pass to go to the bathroom. Some of the students ended up telling the teachers what I did, and I was upset about that. However, I did go to detention so I wouldn't be suspended!

College was the same way. I had a B-plus average at the Sawyer School in 1999–2000 in Woonsocket. My classes were fairly easy (with the exception of a C in Records Management) with A grades most of the way, but some of my college students ridiculed me, too! (Usually, college students are supposed to act their age!) In my case, a lot of immature people failing had to make my life a bit hard because I was passing! The teachers, however, were more understanding and caring, as I even presented work on autism in one or two classes.

Autism is an often-misunderstood disorder because it seems like everyone is not informed. People who are autistic can understand their own world, but others who are not autistic can't. I'd like to be a voice for all autistics all over the world so they can understand where I'm coming from. I may be different from other people, but that won't stop them from being supportive of what I do. It is time that a person with autism speaks and everyone else needs to listen.

Community Resources and Websites

The complexity of symptoms and needs that affect an individual with an ASD also impact the family. In addition to treatment and education for the child with an ASD, family support, parent training, in-home therapy, advocacy, and other support services are critical components of overall treatment of ASDs. It is important that families of a child with special health care needs, including ASDs, have a strong support network of community resources. Fortunately, there are a number of resources available in Rhode Island for children with ASDs as well as for their families. Understanding the different services that each community agency or organization provides allows families to access the services that meet the specific needs of their child.

This section of the guide provides a listing of some of the community supports and websites that are available locally. The organizations listed in this section can be contacted by mail or by telephone. If you have a computer, you will be able to access a great deal of information by going to their websites. Many of these organizations have up-to-date information on ASDs.



Summary of Rhode Island Community Resources By Type of Service

Below is a summary table of community resources available in Rhode Island, organized by type of service(s) provided. This table is provided to help you quickly identify appropriate agencies for the kind of service(s) or support that you or your child with an ASD needs. The next section, Alphabetical List of Rhode Island Community Resources, starting on page 69, provides a full description of and contact information for each agency listed in the table.

EVALUATION, ASSESSMENT, DIAGNOSIS	» Bradley Hospital (page 75)
	» CEDARR Family Centers (page 76)
	» Childhood Communication Services (page 77)
	» The Children’s Neurodevelopment Center at Rhode Island Hospital (page 78)
	» Early Intervention Programs (page 78)
	» The Groden Center, Inc. (page 81)
	» NeuroDevelopment Center of Providence (page 90)
	» Neurodevelopmental Center of Memorial Hospital (page 90)

See Sections 2 and 4 for more information about Evaluation, Assessment, and Diagnosis.

SERVICE COORDINATION/ RESOURCE CENTERS	» The Autism Project of Rhode Island (page 74)
	» CEDARR Family Centers (page 76)
	» Child Adolescent Service System Program (CASSP) (page 77)
	» Early Intervention Programs (page 78)
	» The Groden Center, Inc. (page 81)
	» Paul V. Sherlock Center on Disabilities (page 93)
	» Pediatric Practice Enhancement Project (PPEP) (page 94)
	» Rhode Island Parent Information Network (RIPIN) (page 98)
	» Tech ACCESS of Rhode Island (page 100)

SUPPORT FOR PARENTS AND FAMILIES, INCLUDING TRAINING, ADVOCACY, AND RESEARCH	» The Autism Project of Rhode Island (page 74)
	» Autism Society of America—Rhode Island Chapter (page 74)
	» Child Adolescent Service System Program (CASSP) (page 77)
	» Families for Effective Autism Treatment (FEAT) (page 81)
	» Family Voices of Rhode Island (page 98)
	» Frequent Flyers at Hasbro Hospital (page 81)
	» Autism Speaks (page 89)
	» Parent Support Network of Rhode Island (PSN) (page 91)
	» Paul V. Sherlock Center on Disabilities (page 93)

- » Rhode Island Association for Retarded Citizens (RIARC) (page 97)
- » Rhode Island Developmental Disabilities Council (page 97)
- » Rhode Island Parent Information Network (RIPIN) (page 98)
- » The Sensational Child (page 99)
- » Siblink Program (page 100)
- » Tech ACCESS of Rhode Island (page 100)

EDUCATION

- » Alternative Education Placements (page 108)
- » Early Intervention Programs (page 78)
- » The Groden Center, Inc: Early Intervention Program (page 80)

See Section 3 for more information on Early Intervention Programs.

Section 5 for more information on Education Services.

TREATMENT AND

THERAPEUTIC SERVICES

- » Bradley Hospital (page 75)
- » Early Intervention Programs (page 78)
- » The Groden Center, Inc. (page 81)
- » Home-Based Therapeutic Services (HBTS) (page 83)
- » Kids Connect (page 87)
- » Meeting Street Center (page 88)
- » Pathways Strategic Teaching Center (page 92)
- » Personal Assistance Services and Supports (page 95)

See Section 4 for more information on treatments and interventions.

THERAPEUTIC RECREATION

- » The Autism Project of Rhode Island (page 74)
- » The Sensational Child (page 99)

See page 101 for a list of playgrounds and other recreational programs for children with special health care needs.

TRANSPORTATION SERVICES

- » Ocean State Center for Independent Living (OSCIL) (page 90)
- » PARI Independent Living Center (page 92)
- » RIPTA Ride Share Program (page 99)

LEGAL ASSISTANCE/ADVOCACY

- » Advocates in Action (page 74)
- » Commission for Human Rights (page 78)
- » Rhode Island Disability Law Center (page 98)

VOCATIONAL ASSISTANCE/ TRANSITIONAL SERVICES

- » Autism Spectrum Disorders (ASD) Support Center;
Rhode Island Technical Assistance Project at
Rhode Island College (page 75)
- » The Groden Center, Inc. (page 81)
- » Office of Rehabilitation Services (page 91)
- » Regional Transition Centers (page 96)
- » The Sensational Child (page 99)

Alphabetical List of Rhode Island Community Resources

ADVOCATES IN ACTION (STATEWIDE SELF-ADVOCACY GROUP)

PO Box 41528, Providence, RI 02940-1528

Phone: (401) 785-2028

TDD: (800) 745-5555

Website: www.aina-ri.org

THE AUTISM PROJECT OF RHODE ISLAND

The Autism Project is a unique collaboration of parents and professionals whose mission is to create a comprehensive system of services to support individuals with ASD, their families, and the professionals who support and educate them. The Autism Project achieves this mission by providing a Parent Resource Center, social skill groups, a two-week summer camp, a Volunteer/Mentoring program for teens with Asperger's Syndrome, multiple levels of training for parents and professionals, classroom consultations, workshops, a National Speaker Conference, and by supporting demonstration classrooms for teachers and professionals to visit to view best practices in action.

51 Sockanosset Crossroads, Suite A, Cranston, RI 02920

Phone: (401) 785-2666

Website: www.theautismproject.org

AUTISM SOCIETY OF AMERICA—RHODE ISLAND CHAPTER

The Rhode Island chapter of the Autism Society of America was established in November 2005. Goals include: enhancing community awareness, acceptance, and participation of individuals with ASD; keeping updated on legislative activity; maintaining a supportive, informative network comprised of parents, teachers and community leaders. Chapter activities include community awareness, advocacy, and fund raising.

PO Box 16603, Rumford, RI 02916

Phone: (401) 595-3241

Website: www.autism-society.org

AUTISM SPEAKS

See National Alliance for Autism Research.

AUTISM SPECTRUM DISORDERS (ASD) SUPPORT CENTER

RHODE ISLAND TECHNICAL ASSISTANCE PROJECT AT THE DEPARTMENT OF EDUCATION

The ASD Support Center offers services and support to individuals with ASDs, professionals, and families. Elements of support include: personnel preparation (course work at Rhode Island College), professional development opportunities, workshops and in service training, technical assistance/job embedded support to classrooms and/or individuals, a resource library and website, best practice guidelines, demonstration classrooms and an ASD Network.

RIDE Office of Special Populations

255 Westminster Street, Providence, RI 02903

Phone: (401) 222-8984

Fax: (401) 222-6030

Website: www.ritap.org

BRADLEY HOSPITAL

Bradley Hospital is a not-for-profit hospital that serves children and adolescents that have behavioral, developmental, emotional, and psychological problems. A Lifespan partner and Brown Medical School affiliate, Bradley has established itself as the national center for training and research in child and adolescent psychiatry. Services at Bradley Hospital include the following:

- » Evaluation and assessment for ASD
- » Inpatient Services, ages 2–18
- » Residential Services, ages 5–12
- » Outpatient services, psychiatric and therapeutic
- » Emergency Services, 24 hours a day
- » Crisis Services, evaluation and referral
- » Developmental Disabilities Program, ages 4–22
- » Special Education Services for children ages 3–21, a referral is made through your local school department

1011 Veterans Memorial Parkway, East Providence, RI 02915

Phone: (401) 432-1000

Fax: (401) 432-1500

Website: www.bradleyhospital.org

CEDARR FAMILY CENTERS

CEDARR stands for Comprehensive, Evaluation, Diagnosis, Assessment, Referral and Re-evaluation. CEDARR Family Centers (CFCs) can provide families of children with special health care needs with information, clinical expertise, connection to community supports, and assistance to help them meet the needs of their child. CEDARR Family Center services are available to all children and families in the State of Rhode Island.

The services available through the CEDARR Family Centers include basic services and supports, specialized clinical evaluation, family care plan development, crisis intervention services, and family care coordination assistance. This includes Direct Services if determined appropriate by the CEDARR Family Center. Direct Services include: Home Based Therapeutic Services (HBTS), Personal Assistant Services and Supports (PASS), and Kids Connect (formally Therapeutic Child and Youth Care).

For more information about CEDARR Family Centers, visit the Rhode Island Department of Human Services website at www.dhs.ri.gov, or contact the Rhode Island Department of Human Services at (401) 462-5300. There are currently, four CEDARR Family Centers in Rhode Island, and each serves families statewide. Families can choose the CEDARR Family Center that best meets the needs of their child and family.

About Families, CEDARR Family Center

203 Concord Street, Suite 335, Pawtucket, RI 02860

Phone: (401) 365-6855

Fax: (401) 365-6860

Website: www.aboutfamilies.org

About Families Satellite 1

1 Cumberland Street, 4th Floor, Woonsocket, RI 02895

Phone: (401) 671-6533

Fax: (401) 671-6532

About Families Satellite 2

1 Frank Coelho Drive, Portsmouth, RI 02871

Phone: (401) 683-3570

Empowered Families CEDARR Family Center

82 Pond Street, Pawtucket, RI 02860

Phone: (401) 365-6103 or (888) 881-6380

Fax: (401) 365-6123

www.empowerdfamilies.org

Families First CEDARR Center

Hasbro Children's Hospital, Room 120, 593 Eddy Street, Providence, RI 02903

Phone: (401) 444-7703

Fax: (401) 444-6115

Family Solutions CEDARR

134 Thurbers Avenue, Suite 102, Providence, RI 02905

Phone: (401) 461-4351 or (800) 640-7283

Fax: (401) 461-4953

Website: www.solutionscedarr.org

CHILD ADOLESCENT SERVICE SYSTEM PROGRAM (CASSP)

CASSP is a network of 8 Local Coordinating Councils (LCCs) that bring together parent advocates, children's service agencies, and other community partners concerned with the needs of children and their families. CASSP is available statewide to families who have children ages birth to 21, who have serious emotional or behavioral challenges, have had or have the potential to have the disability for more than one year, and are already in or at risk for out-of-home placement. The goal of CASSP is to prevent families from becoming separated and to maintain children in their home communities. To make a referral to CASSP, call the local LCC serving your area:

Providence: (401) 421-6993

Pawtucket/ Central Falls: (401) 722-5573 x252

East Bay: (401) 848-6363

Kent County: (401) 732-5656

Metro West: (401) 784-3600

Washington County: (401) 789-1166

Northern Rhode Island: (401) 762-3429

CHILDHOOD COMMUNICATION SERVICES

Barry Prizant, Ph.D., CCC-SLP (Certified Speech-Language Pathologist) is a private specialist who specializes in the diagnosis of children with ASD. Dr. Prizant also does communication and educational consultations in homes or schools.

Barry M. Prizant, Ph.D., CCC-SLP (Certified Speech- Language Pathologist)

2024 Broad Street, Cranston, RI 02905

Phone: (401) 467-7008

Fax: (401) 383-3980

Email: Bpriznat@aol.com

Website: www.barryprizant.com

THE CHILDREN'S NEURODEVELOPMENT CENTER AT RHODE ISLAND HOSPITAL

(FORMERLY KNOWN AS THE CHILD DEVELOPMENT CENTER)

The Children's Neurodevelopment Center (CNDC) offers evaluations of children, birth to age 21, by a team of specialists for diagnosis and treatment recommendations. The Center utilizes a team approach that allows for coordination between specialists for evaluation, assessment, and diagnosis. The Children's Neurodevelopment Center is staffed with specialists in the areas of education, nutrition, hearing, speech, occupational therapy, genetics, physical therapy, developmental pediatrics, neurology, psychology, nursing, and social services. Consults from other pediatric specialists are also available, including neurosurgery, orthopedics, urology, and otolaryngology. Initial referral of a child to the CNDC should be made by the child's primary care physician.

Evaluation, diagnosis, and treatment recommendations, once completed, are discussed with the family and provided in a written report for the family. The report can be made available (with family permission) to physicians, schools, and other agencies that may be involved with the child. The Center also provides ongoing medical care for children with ASDs and other neurodevelopmental disabilities.

593 Eddy Street, Providence, RI 02903

Phone: (401) 444- 5685

Fax: (401) 444-6115

Website: www.lifespan.org

COMMISSION FOR HUMAN RIGHTS

The objective of the Commission for Human rights is to enforce ant-discrimination laws mandated by state and federal law.

10 Abbot Park Place, Providence, RI 02903

Phone: (401) 222-2661

Fax: (401) 222-2616

TDD: (401) 222-2664

EARLY INTERVENTION PROGRAM

Each state is mandated to provide an Early Intervention Program for children with developmental delays (birth to three years of age) in accordance with a federal law entitled the Individuals with Disabilities Education Act (IDEA). In Rhode Island, the Rhode Island Department of Human Services administers the Early Intervention Program.

Early Intervention (EI) is a family-centered program that promotes the growth and development of infants and toddlers with developmental challenges. EI serves all eligible children (birth to age three years of age) and their families, regardless of income or health insurance coverage. All EI sites provide services to children with an ASD and their families. Services are individualized to support and assist families in meeting the goals that they have for their child. Referrals for a child who has an ASD or symptoms of an ASD can be made directly to EI programs by family members, guardians, primary care physicians, and community agencies for infant and toddler screening, evaluation, and assessment to determine eligibility for services.

Children’s Friend and Service

621 Dexter Street, Central Falls, RI 02863

Phone: (401) 721-9200

Fax: (401) 729-0010

Website: www.cfsri.org

Easter Seals

5 Woodruff Avenue, Narragansett, RI 02882

Phone: (401) 284-1000

Fax: (401) 284-1006

Website: www.eastersealsri.com

Family Resource Community Action

245 Main Street, Woonsocket, RI 02895

Phone: (401) 766-0900

Fax: (401) 766-8737

Website: www.famresri.org (look under “How We Can Help”)

Family Service

134 Thurbers Avenue, Providence, RI 02905

Phone: (401) 331-1350

Fax: (401) 277-3388

Website: www.familyserviceri.org

Hasbro Children’s Hospital

593 Eddy Street, Providence, RI 02903

Phone: (401) 444-3201

Fax: (401) 444-6115

Website: www.lifespan.org/partners/hch

J. Arthur Trudeau Memorial Center

Kent County Chapter ARC, 250 Commonwealth Avenue, Warwick, RI 02886

Phone: (401) 823-1731

Fax: (401) 823-1849

Website: www.kentcountyarc.org

J. Arthur Trudeau Memorial Center

South County Early Intervention Program

140 Point Judith Road, Unit 44, Narragansett, RI 02882

Phone: (401) 783-6853

Fax: (401) 783-6846

Website: www.kentcountyarc.org

James L. Maher Center

120 Hillside Avenue, Newport, RI 02840

Phone: (401) 848-2660

Fax: (401) 847-9459

Website: www.mahercenter.org

Meeting Street Center

667 Waterman Avenue, East Providence, RI 02914

Phone: (401) 438-9500

TTY: (401) 438-3690

Fax: (401) 431-6639

Website: www.meetingstreet.org/matriarch

The Groden Early Intervention Center

If your child has symptoms of autism or a diagnosis of an ASD, the EI site you select may refer your child to Groden EI. The Groden Center, Inc., founded in 1976, is a non-profit agency that serves individuals with ASDs of all ages. The Groden Center EI program is the only EI site in Rhode Island that is designed to work specifically with children with ASD. The Groden Center does not provide families and children with full services, but works with an EI full-service provider to coordinate all needed services.

86 Mount Hope Avenue, Providence, RI 02906

Phone: (401) 274-6310

Fax: (401) 421-3280

Website: www.grodencenter.org

See page 81 for more information about the Groden Center.

FAMILIES FOR EFFECTIVE AUTISM TREATMENT (FEAT)

FEAT Rhode Island is a non-profit organization of parents. Their mission is to inform parents about effective intervention based on Applied Behavior Analysis (ABA). FEAT strives to disseminate accurate information about ABA, to promote the development and quality of programs, as well as to guide, support, and advocate for families seeking this type of intervention. In addition to supporting families, FEAT offers an annual conference, a guest speaker series throughout the year, and a lending library.

P.O. Box 8460, Cranston, RI 02920

Phone: (401) 886-5015

Fax: (401) 739-7384

Email: info@featri.org

Website: www.featri.org

FREQUENT FLYERS AT HASBRO HOSPITAL

Frequent Flyers is a service available for children with special health care needs and their families. The purpose of Frequent Flyers is to facilitate admission to the hospital for children with frequent admissions. Any family with a child who is a frequent user of Lifespan hospital (RI Hospital, Hasbro Children's Hospital, Miriam Hospital, Bradley Hospital, and Newport Hospital) can access this service. Frequent Flyers is a database that families can add to. The database consists of a summary of the child's medical conditions, medications and allergies, common presenting problems, and how they are managed. It also includes the families' comments, child's photo, primary and specialty physicians, home care providers and emergency contacts. Parents are provided with a secure home-based access to their child's database and can email or send in updates.

Family Center at Hasbro Children's Hospital

593 Eddy Street, Providence, RI

Phone: (401) 444-3201

Website: www.lifespan.org

THE GRODEN CENTER, INC.

The Groden Center, Inc., the largest provider in Rhode Island of services dedicated to individuals with ASDs, was founded in 1976 with a mission to support, teach, nurture, and challenge individuals with ASDs to reach their greatest level of independence, productivity, and participation in their communities. A variety of programs accomplish this goal by providing the most effective educational and therapeutic services, by advancing knowledge and best practices through research, education, and training, and by involving, educating, and supporting families in caring for and advocating for their children.

The following list of programs offered by the Groden Center reflects the continuum of supports that have been developed to meet the variety of needs of individuals with ASDs throughout their lifespan.

The Community Support Services Department provides on site evaluation, treatment, training, and consultation services to schools, group homes, families, and other agencies or treatment providers involved in the assessment and treatment of children and adults with developmental and/or behavioral disabilities. Direct treatment services in the form of individual or group-based skills development training are also provided in school settings. The CSS department also offers group therapy services for individuals with social disabilities during the summer months. A social club and therapy group is available throughout the school year for young adolescents with Asperger Disorder. Diagnostic, psychological and behavioral evaluations are also conducted through the CSS department.

The Groden Center Day School serves children between the ages of 3–21 from Rhode Island and neighboring states. It operates 12 months a year and provides instruction in functional skill development, communication, emotional and social development, physical and recreational skills, and vocational education. The school also runs a Saturday therapeutic recreation program.

The Groden Center’s Early Intervention Program (EIP) is part of a statewide network of regional Early Intervention Programs and specializes in working with infants and toddlers with a diagnosis of an ASD. Services, which must be accessed through the full service early intervention provider, include home visiting, playgroups, and parent support groups.

Home-Based Treatment Services are supplied through two programs: Children’s Intensive Treatment (CIT) and In-home Support and Training (IST). CIT offers structured learning opportunities for children from 3–6 years of age who have morning and/or early afternoon hours available for therapy in their homes. The goal of the program is to prepare children behaviorally and academically for placement in the least restrictive school setting possible. IST services provide assistance with behavior therapy and instructional strategies in homes and relevant community settings to children ages 7–21 and families. Families are taught practical behavioral strategies that are effective with their children; children are taught functional skills and coping strategies to gain self-control and to foster independence. Children helped through IST services are typically challenged by serious behavioral concerns related to ASDs. Referrals to HBTS programs must originate through a CEDARR Family Center.

The Livingston Center Preschool and Daycare Center opened in 1998 with the purpose of fully integrating children of differing abilities. At capacity, the preschool can serve 20 children, 6 of whom are typically children with disabilities. The preschool program emphasizes ongoing, individualized assessment of progress by an interdisciplinary team, communication with families, and a balance of 1:1 of small group and large group activities.

The Professional Family Living Arrangement (PFLA) program is a therapeutic foster care program working to keep children and youth in home settings while providing intensive and highly specialized behavioral and therapeutic services. PFLA handles short- and long-term placement of children and youth with challenging behaviors and developmental disabilities through the Department of Children, Youth, and Families.

Residential Programs are available for adolescent students of the Day School who are in need of alternative living arrangements. There are currently 4 homes serving 17 boys and 3 girls in residences located in both suburban and rural settings.

The Vocational Training and Employment Program assists individuals in discovering their employment interests and aptitudes. This program offers a variety of assessment and training activities, can include job coaching, and may lead to part-time or full-time employment. It can be done on a part-time or full-time basis, and in coordination with other educational or support services.

The Groden Center participates in selected research activities and provides adult programs, both day and residential, in Massachusetts (The Halcyon Program) and Rhode Island (The COVE Center).

86 Mount Hope Avenue, Providence, RI 02906

Phone: (401) 274-6310

Fax: (401) 421-3280

Website: www.grodencenter.org

HOME-BASED THERAPEUTIC SERVICES (HBTS)

Home-Based Therapeutic Services is a CEDARR direct service for children living at home who have Medicaid coverage and have been diagnosed with moderate to severe physical, developmental, behavioral or emotional conditions. Specialized services are provided in accordance with an approved individualized treatment plan. The goal of this service is to enhance the child's ability to participate within the family and community. Enhanced HBTS services allow parents of children waiting for HBTS to receive some intervention services prior to specialized treatment. HBTS services are accessed through CEDARR Family Centers. The following is a current list of Home-Based Therapeutic providers:

Adeline LaPlante Memorial Center

1130 Ten Rod Road, Bldg A, Suite 207, North Kingstown, RI 02852

Phone: (401) 295-2250

Fax: (401) 295-2260

The Arc of Northern Rhode Island

1 Cumberland Street, 4th floor, Woonsocket, RI 02895

Phone: (401) 775-1500

Fax: (401) 762-1957

Website: www.arcofnri.org

Bradley Hospital

Home-Based Treatment Program

1011 Veterans Memorial Parkway, East Providence, RI 02915

Phone: (401) 432-1528

Fax: (401) 432-1500

Website: www.lifespan.org/partners/bh

Bradley Hospital

Intensive Behavioral Treatment–IBT

1011 Veteran’s Memorial Parkway, East Providence, RI 02915

Phone: (401) 432-1175 or 432-1225

Fax: (401) 432-1500

Website: www.lifespan.org/partners/bradley/

Cranston ARC

111 Comstock Parkway, Cranston, RI 02921

Phone: (401) 632-0264

Fax: (401) 383-8751

Website: www.cranstonarc.org

Family Service of RI

55 Hope Street, Providence, RI 02906

Phone: (401) 331-1350

Fax: (401) 277-3387

Website: www.familyserviceri.org

Frank Orleans Center
93 Airport Road, Westerly, RI 02891
Phone: (401) 315-0143
Fax: (401) 315-0201
Website: www.oleancenter.org

Groden Center, Inc.
Children's Intensive Treatment Program
610 Manton Avenue, Providence, RI 02909
Phone: (401) 274-6310
Fax: (401) 421-2152
Website: www.grodencenter.org

Groden Center, Inc.
In-Home Support and Training Program (IST)
610 Manton Avenue
Providence, RI 02909
Phone: (401) 274-6310
Fax: (401) 421-2152
Website: www.grodencenter.org

John Hope Settlement House-HBTS
7 Burgess Street, Providence, RI 02903
Phone: (401) 421-6993
Fax: (401) 454-5619
Website: www.johnhope.org

Kent County Chapter RIARC
Arthur Tredeau Memorial Center
3445 Post Road, Warwick, RI 02886
Phone: (401) 739-2700
Fax: (401) 732-8907
Website: www.kentcountyar.org

Looking Upwards, Inc.
438 East Main Road, Middletown, RI 02842
Phone: (401) 847-0960
Fax: (401) 849-0290
Website: www.lookingupwards.org

Ocean State Community Resources, Inc.
25 West Independence Way-Suite G, Kingstown, RI 02881
Phone: (401) 789-4614
Fax: (401) 789-1957

Perspectives Youth and Family Services Behavioral Health Program
1130 Ten Rod Road, Bldg. C, Suite 201, North Kingston, RI 02852
Phone: (401) 294-8181
Fax: (401) 294-7773

Perspectives Youth and Family Services Behavioral Health Program
ABA Program–Early Intensive Behavioral Intervention
1130 Ten Rod Road, Bldg. C, Suite 201, North Kingston, RI 02852
Phone: (401) 294-8181
Fax: (401) 294-7773

Perspectives Youth and Family Services
Deaf and Hard of Hearing program
1130 Ten Rod Road, Bldg. C, #201, North Kingston, RI 02852
Phone: (401) 294-8181
Fax: (401) 294-7773
Website: www.perspectivescorporation.com

Spurwink RI
935 Park Avenue, Cranston, RI 02910
Phone: (401) 781-4380
Fax: (401) 467-3261
Website: www.spurwinkri.org

TIDES Family Services
215 Washington Street, West Warwick, RI 02893
Phone: (401) 822-1360
Fax: (401) 823-4694
Website: www.tidesfs.org

United Cerebral Palsy of Rhode Island, Inc. (UCP of RI)
200 Main Street, Suite 210, P.O. Box 36, Pawtucket, RI 02862
Phone: (401) 728-1800
Fax: (401) 728-0182
Website: www.UCPRI.org

KIDS CONNECT (FORMALLY THERAPEUTIC CHILD AND YOUTH CARE)

Kids Connect is a CEDARR direct service that provides therapeutic services delivered in licensed child care centers for certain Medicaid-eligible children and youth (6 weeks to 19 year of age) with serious behavioral, developmental or physical needs. The purpose of Kids Connect is to enable children and youth with special health care needs to participate in child and youth care settings with their peers. This service is designed as a less restrictive and more inclusive alternative or complementary service to HBTS. Kids Connect services are accessed through CEDARR Family Centers. The following is a list of Kids Connect Providers:

Child Care Connection

151 Hunt Street, Central Falls, RI 02863

Phone: (401) 475-5747 or (401) 727-4474

Fax: (401) 475-5719

Website: www.childcareconnect.com

Child Care Connection

197 Beverage Hill Avenue, Pawtucket, RI 02860

Phone: (401) 724-0494

Child Care Connection

42 Greco Lane, Warwick, RI 02885

Phone: (401) 732-1120

Child Care Connection

22 Cedar Swamp Road, Smithfield, RI 02917

Phone: (401) 233-2828

Child Care Connection

25 Blackstone Valley Place, Lincoln, RI 02865

Phone: (401) 334-2210

Child, Inc.

160 Draper Avenue, Warwick, RI 02889

Phone: (401) 737-0403

Fax: (401) 737-2302

Website: www.childincri.org

Child, Inc.

849 Centerville Road, Warwick, RI 02886

Phone: (401) 823-3777

Fax (401) 823-5908

Child, Inc.

28 Payan Street, West Warwick, RI 02893

Phone: (401) 828-2888

Fax: (401) 826-4887

Child, Inc.

23 Cady Street, Coventry, RI 02816

Phone: (401) 823-3228

Fax: (401) 826-8920

Kids Klub

462 Smithfield Avenue, Pawtucket, RI 02860

Phone: (401) 475-7707

Fax: (401) 475-4832

Website: www.compservicesri.com

Meeting Street

667 Waterman Avenue, East Providence, RI 02914

Phone: (401) 438-9500

Fax: (401) 438-3760

Website: www.meetingstreet.org

Crayons Child Care and Family Services, Inc.

3445 Post Road, Warwick, RI 02886

Phone: (401) 738-7081

Fax: (401) 737-8097

MEETING STREET CENTER

Meeting Street Center offers children and families a personalized and comprehensive approach to making the most of this very important time in a child's growth and development. Founded in 1946, Meeting Street helps children and young adults with special health care needs and their families meet the challenges in their lives.

Meeting Street services encompass all areas of development, including communication, motor and planning skills, social skills, and health and family needs. Understanding that every family is unique, Meeting Street staff works with children to apply interventions into their everyday routines and integrates learning into the child's natural environment. Specialized Services for children with ASDs and other social communication disorders include:

The Early Intervention Program (EI) provides evaluations, therapeutic services and support for children from birth to age three and for their families. The largest provider of EI services in Rhode Island, Meeting Street offers children and families a highly personalized, comprehensive and kindhearted approach to this very important step in early development.

More Than Words—The Hanen Program for Parents of Children with Autism Spectrum Disorders is an eleven-week program that teaches parents practical tools to help children learn to communicate.

Therapeutic Listening is a technique that uses sound stimulation through music, in combination with Sensory Integration treatment techniques, to decrease sensory defensive behaviors, increase attention span, calm and organize, and improve communication.

Sensory Integration Therapy: Therapists work with families in their home to help them understand sensory issues and how they affect the child, and to teach them how to use specific techniques in daily routines.

Picture Exchange Communication Systems: Nonverbal children with ASDs are taught communication skills through this method. Children are taught to identify symbols and to use them to communicate instead of spoken language.

667 Waterman Avenue, East Providence, RI 02914

Phone: (401) 438-9500

Fax: (401) 438-3760

Website: www.meetingstreet.org

NATIONAL ALLIANCE FOR AUTISM RESEARCH/AUTISM SPEAKS

Autism Speaks (AS) is a non-profit organization dedicated to funding global biomedical research into the causes, prevention, treatments, and cures for autism; to raising public awareness about autism and its effects on individuals, families, and society; and to bringing hope to all who deal with the hardships of this disorder. AS aims to bring the autism community together as one strong voice to urge the government and private sector to listen to our concerns and take action to address this urgent global health crisis.

85 School Street, Suite 100, Watertown, MA 02472

Phone: (617) 924-3300

Fax: (617) 924-3311

Website: www.autismspeaks.org

NEURODEVELOPMENT CENTER

The Neurodevelopment Center is a private, multi-disciplinary center that provides traditional and innovative assessment and intervention options for children and adults with neurologically based conditions. These conditions may include Attention Deficit Hyperactivity Disorder (ADHD), Anxiety, Autism Spectrum Disorders (ASDs), Obsessive Compulsive Disorder (OCD), learning disabilities, behavioral problems, and other neurological difficulties.

260 West Exchange Street, Suite 302, Providence, RI 02903

Phone: (401) 351-7779

Website: www.neurodevelopmentcenter.com

NEURODEVELOPMENTAL CENTER OF MEMORIAL HOSPITAL OF RHODE ISLAND

The Neurodevelopmental Center is an internationally recognized program that treats children with behavioral, learning, and developmental disabilities. Promoting success for children is the program's goal. The professionals treat children with Tics & Tourette Syndrome, Attention Deficit Hyperactivity Disorder, Obsessive Compulsive Behavior, Pervasive Developmental Disorders, ASDs, Asperger Disorder, Learning Disabilities, Traumatic Brain Injury, Cerebral Palsy, Post Prematurity, and Cancer or Seizure Disorders (on referral).

555 Prospect Street, Pawtucket, RI

Phone: (401) 729-6200

Website: www.mhriweb.org

OCEAN STATE CENTER FOR INDEPENDENT LIVING (OSCIL)

OSCIL is a community-based resource center that helps transport individuals with long-term health issues to services and supports in the community.

59 West Shore Road, Warwick, RI 02889

Phone: (401) 738-1013 or Kingston Office (401) 782-9400

TDD: (401) 738-1015

Fax: (401) 738-5118

Hispanic Program: (401) 738-5118

Website: www.oscil.org

OFFICE OF REHABILITATION SERVICES

The DHS Office of Rehabilitation Services (ORS) provides Rhode Islanders who have disabilities with a comprehensive program of rehabilitation, social and independent living services. To fulfill its mission of empowering individuals with disabilities to choose, prepare for, obtain and maintain employment, economic self-sufficiency, independence and integration into society, ORS administers the following programs and services:

Vocational Rehabilitation (VR)—designed to assist individuals who have a disability, making it difficult for them to work, to choose, prepare for, find and maintain employment.

Disability Determination Services (DDS)—determines the medical eligibility of children and adults with disabilities who are applying for cash benefits under the federal program for Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI).

Assistive Technology Access Partnership (ATAP)—designed to remove barriers and to increase access to assistive technology devices and services for individuals with disabilities.

Office of Rehabilitation Services

40 Fountain Street, Providence, RI 02903

Phone: (401) 421-7005

TDD: (401) 421-7016

Spanish: (401) 272-8090

Fax: (401) 222-3574

Website: www.ors.ri.gov

PARENT SUPPORT NETWORK OF RHODE ISLAND (PSN)

PSN is a statewide organization of families supporting families with children and youth who are at risk for or who have behavioral and/or emotional challenges. They provide support groups, telephone support, educational events, one-on-one assistance with advocacy and/or literature concerning education, mental health, parenting a child with special emotional or behavioral needs, juvenile justice, and substance abuse case support. Meetings are held in various areas across the state. Services are available in Spanish.

Warwick Executive Park, Building F

400 Warwick Avenue, Suite 12, Warwick, RI 02888

Phone: (401) 467-6855 or (800) 483-8844

Fax: (401) 467-6903

Email: psnofri@aol.com

Website: www.psnri.org

PARI INDEPENDENT LIVING CENTER

PARI is a private, not-for-profit, community-based agency whose programs and policies are determined by people with disabilities. The PARI staff works with people with any kind of disability to identify goals and to provide training, equipment, advocacy and counseling to help them achieve their goals. PARI will help the client seek medical resources, transportation, housing, or ways of becoming involved in the community.

500 Prospect Street, Pawtucket, RI 02860

Phone/TDD: (401) 725-1966

Fax: (401) 725-2104

Website: www.pari-ilc.org

PATHWAYS STRATEGIC TEACHING CENTER

Pathways Strategic Teaching Center is a comprehensive education and treatment program/school serving children with ASDs and related disorders in a site-based setting. Pathways' education and treatment strategies are based on the principles of Applied Behavior Analysis (ABA), an organized and systematic approach that has been demonstrated effective in building skills as well as in assessing and treating problem behavior. Individually-tailored curricula address speech and language, pre-academic and academic skills, daily living and self-care skills, play and social skills, and the treatment of challenging behavior. Pathways is fully certified by the Rhode Island Department of Education as a 230-day special education program for pre-school and elementary-aged children. Pathways Strategic Teaching Center is an affiliated program of the J. Arthur Trudeau Center, Kent County ARC.

J. Arthur Trudeau Memorial Center

3445 Post Road, Warwick, RI 02887

Phone: (401) 739-2700 x275

Fax: (401) 732-8907

Website: www.kentcounty.arc.org

PAUL V. SHERLOCK CENTER ON DISABILITIES

The Paul V. Sherlock Center on Disabilities was founded at Rhode Island College in 1993. It is a member of a national network of interdisciplinary Centers advancing policy and practice for and with individuals with developmental and other disabilities, their families, and communities. The Sherlock Center is charged with four core functions: training, community outreach and service, dissemination of information and research.

Individual and Family Support Initiatives and Programs include: 360 Local Supportive Parenting Project, Rhode Island Services to Children and Youth with Dual Sensory Impairments, Training and Events to Families, newsletter free to families who have a child with a disability, Educational Advocacy Program, Rhode Island Vision Services Education Program, and Family to Family of Rhode Island. The Family to Family Network of Rhode Island Directory is available on the Family to Family website at www.rifamilytofamily.net, or by calling (401) 727-4144 for a copy.

Rhode Island College Institute for Developmental Disabilities

600 Mount Pleasant Avenue, Providence, RI 02908

Phone: (401) 456- 8072

Fax: (401) 456- 8150

TTY: (401) 456-8773

Website: www.sherlockcenter.org



PEDIATRIC PRACTICE ENHANCEMENT PROJECT (PPEP)

A “medical home” initiative sponsored by the Rhode Island Department of Health and Rhode Island Department of Human Services to support Primary Care Pediatric and Family Practices dedicated to serving children with special health care needs and their families. The Pediatric Practice Enhancement Project provides Parent Consultants from Rhode Island Parent Information Network, in selected practices, to assist families in accessing needed information, resources and community services including CEDARR Family Centers. Participating practices include:

Aquidneck Medical Associates

50 Memorial Blvd., Newport, RI 02840

Phone: (401) 847-2290

Fax: (401) 847-9533

Dr. Cheryl Flynn

2 Wake Robin Road, Lincoln, RI 02865

Phone: (401) 333-1656

Fax: (401) 333-3104

Rainbow Pediatrics

593 Eddy Street, Lower Level, Providence, RI 02903

Phone: (401) 444-4691

Fax: (401) 444-7574

Website: www.lifespan.org

Dr. Robert Burke

Memorial Hospital

111 Brewster Street, Pawtucket, RI 02860

Phone: (401) 729-2582

Fax: (401) 729-2854

Website: www.mhri.org

Park Pediatrics

801 Park Avenue, Cranston, RI 02921

Phone: (401) 274-6575

Fax: (401) 273-2597

South County Pediatric Group, Inc.
4979 Tower Hill Road, Wakefield, RI 02879
Phone: (401) 789-6492
Fax: (401) 789-5524
Website: www.southcountypediatrics.com

Thundermist Health Center
450 Clinton Street, Woonsocket, RI 02895
Phone: (401) 767-4100
Fax: (401) 235-6899
Website: www.thundermisthealth.org

Wood River Health Services
823 Main Street, Hope Valley, RI 02832
Phone: (401) 539-0228
Fax: (401) 539-2663
Website: www.woodriverhealth.org

PERSONAL ASSISTANCE SERVICES AND SUPPORTS (PASS)

PASS is a CEDARR direct service that provides consumer-directed services and supports for children with special health care needs who are Medicaid-eligible. In this program, the PASS worker is recruited and supervised by the family, who receives support from a PASS Family Support Agency. This service focuses on increasing the child's ability to accomplish activities of daily life, make self-preserving decisions, and participate in social roles and settings. The assistance provided to the child by the PASS worker includes hands-on assistance (performing a personal care task for a child) or cuing so that the child performs the task by him/herself. PASS Services are accessed through CEDARR Family Centers. The following is a list of PASS providers:

The Arc of Northern Rhode Island
1 Cumberland Street, 4th floor, Woonsocket, RI 02895
Phone: (401) 775-1500
Fax: (401) 762-1957
Website: www.arcofnri.org

Kent County Chapter RIARC
Arthur Trudeau Memorial Center
3445 Post Road, Warwick, RI 02887
Phone: (401) 739-2700
Fax: (401) 732-7899
Website: www.kentcountyar.org

United Cerebral Palsy of Rhode Island
200 Main Street, Pawtucket, RI 02860
Phone: (401) 728-1800
Fax: (401) 728-0182
Website: www.UCPRI.org

REGIONAL TRANSITION CENTERS

The RI Regional Transition Centers provide information, training and technical assistance to teachers, administrators and families of students in special education, ages 14–21, who are preparing for the transition from school to adult life. The Centers offer a resource and curriculum library and coordinate regional training and information events through their Regional Transition Advisory Committee (TAC).

East Bay Collaborative

Serves: Barrington, Portsmouth, Bristol, Warren, Tiverton, Newport, East Providence,
Little Compton, Middletown
317 Market Street, Warren, RI 02885
Phone: (401) 245-2045
Fax: (401) 245-9332

Northern RI Collaborative

Serves: Burrillville, North Providence, Central Falls, North Smithfield, Smithfield,
Cumberland, Pawtucket, Johnston, Lincoln, Woonsocket
2352 Mendon Road, Cumberland, RI 02864
Phone: (401) 658-5790
Fax: (401) 658-4012

Providence Public Schools

Serves: Providence
797 Westminster Street, Providence, RI 02903
Phone: (401) 278-0520

Southern Rhode Island Collaborative

Serves: Block Island, Charlestown, North Kingstown, East Greenwich, South Kingstown,
Exeter, West Greenwich, Jamestown, Narragansett, Westerly
646 Camp Street, North Kingstown, RI 02852
Phone: (401) 295-2888
Fax: (401) 295-3232

West Bay Collaborative

Serves: Coventry, Warwick, Cranston, West Warwick, Foster, Glocester, Scituate

144 Bignall Street, Warwick, RI 02888

Phone: (401) 941-8353

Fax: (401) 941-8535

RHODE ISLAND ASSOCIATION FOR RETARDED CITIZENS (RIARC)

The Rhode Island Association for Retarded Citizens is an advocacy agency for individuals with mental retardation or other developmental disabilities.

99 Bald Hill Road

Cranston, RI 02920

Phone: (401) 463-9191

Website: www.arcofnri.org

RHODE ISLAND DEVELOPMENTAL DISABILITIES COUNCIL

Rhode Island Developmental Disabilities Council promotes creative ways for men, women, and children with disabilities to live more independent, fulfilling lives.

400 Bald Hill Road Suite 515, Warwick, RI 02886

Phone: (401) 737-1238

Fax: (401) 737-3395

TTY: (401) 737-1238

Website: www.riddc.org



RHODE ISLAND DISABILITY LAW CENTER

The Rhode Island Disability Law Center provides free legal assistance for individuals and families of children with disabilities. Services include individual representation to protect rights or secure benefits and services, self-help information, educational programs and administrative and legal advocacy.

349 Eddy Street, Providence, RI 02903

Phone: (401) 831-3150, (800) 733- 5332

TTY: (401) 831-5335

Fax: (401) 274-5568

Website: www.ridlc.org

RHODE ISLAND PARENT INFORMATION NETWORK (RIPIN)

Rhode Island Parent Information Network provides information, referral, and support for all families—whether or not their children have special needs. Workshops are offered on parenting, special education, early interventions, and transitions from one service system to another. RIPIN provides information and support about early intervention programs, home visiting programs for young children, as well as individual advocacy and support for health and special issues. RIPIN also has a lending library of books, videotapes, and audiotapes on various topics of interest to families of children with special needs and typically developing children. Some of the programs RIPIN offers are:

Family to Family connects families of children and adults with special needs with other families who have similar needs and experiences. This gives families the opportunity to share information and support and to get information on local, state, and national resources for families. For more information, visit the Family to Family website at www.rifamilytofamily.net.

Family Voices (FV) of Rhode Island offers health information, advocacy, training and support to help families learn about their child's illness or disability, and ultimately, seek positive outcomes for their child and family. Family Voices is part of a national network of families and friends of children with disabilities and/or chronic illnesses. For more information, visit the RIPIN website at www.ripin.org.

Fathers 1st is a unique program that offers support to fathers, stepfathers, grandfathers and any other male who cares about children with special needs. Mike Masse, the founder of Father's 1st, offers a support group once a month in Woonsocket. For more information, visit the Father's 1st website at www.fathers1st.org.

The Home Instruction Program for Preschool Youngsters (HIPPY) is a statewide visiting program for parents of children from 3-5 years of age. HIPPY supports the development of school readiness through cognitive skill building, information about the local school district, parent-networking opportunities, and by connecting families to community resources. For more information, visit the RIPIN website at www.ripin.org.

The Parents as Teachers (PAT) program is designed to provide parents of children from before birth to age five, the information and support they need to give their children the best possible start in life. Parents As Teachers offers regularly scheduled home visits by certified parent educators. There is no fee for participation. Parents As Teachers has programs in 19 communities, in 11 school districts and at 17 community-based agencies. For more information, visit the Parents as Teachers website at www.parentasteachers.org.

RIPTA RIDE SHARE PROGRAM

RIPTA provides transportation for individuals with special health care needs. For service, you must call 48 hours in advance.

269 Melrose, Providence, RI 02907

Phone: (800) 827-2127

Website: www.ripta.com

THE SENSATIONAL CHILD

The Sensational Child is a non-profit organization supporting families and their children with special needs. The organization's mission is to reach out to families and their children from diagnosis through transition to adulthood.

Better public understanding and the creation of family support systems occur through parent-to-parent group meetings, playgroups, enrichment programs, educational opportunities, speaker nights, book clubs and art instruction. Many of the groups meet in the sensory room, where children both with disabilities and their typical peers can meet on an equal footing in a uniquely stimulating environment.

The Sensational Child, a durable medical equipment provider, is a source for therapy tools and equipment, books devoted to special needs, quality developmental toys, items used in sensory integration therapy, as well as adaptive equipment for better organizational, daily living and life skills.

The Sensational Child is also a training site that provides vital work experience for adults with special needs to learn valuable skills in a nurturing environment.

Ultimately, the aim of the Sensational Child is to ensure a welcoming atmosphere, free from intimidation, where the complex world of disability can be navigated and support can be found by interacting with people who have been on a similar quest for the right information, the best therapy, and the better understanding.

Lafayette Mill Complex
650 Ten Rod Road, North Kingstown, RI 02852
Phone: (401) 667-2797
Fax: (401) 667-2788
Website: www.sensationalchild.org

SIBLINK PROGRAM

The Siblink Program at Hasbro Children's Hospital provides support to siblings of children with special health care needs. The Siblink support program brings siblings together to share experiences so they can better cope with their feelings and with the situations that arise from their brother's or sister's condition. The Siblink Program is open to all families who have children with special health care needs. Families are welcome no matter where their children receive their health care.

The Bradley Hasbro Research Center
Coro West, Suite 204
1 Hoppins Street, Providence, RI 02903
Phone: (401) 793-8993
Website: www.lifespan.org/news/2003/08/HCH_Siblink_8_29_03.htm

TECHACCESS OF RHODE ISLAND

TechACCESS of Rhode Island is a private, non-profit resource center that serves individuals with disabilities who are interested in assistive technology. Information and referral services regarding assistive technology products, funding, and services are provided at no charge. TechACCESS also provides referrals to service providers, vendors, and advocacy services.

110 Jefferson Boulevard, Suite 1, Warwick, RI 02888-3854
Phone: (401) 273-1990, 401 463-0202 or 800-916-8324
TTY: (401) 273-1990, (401) 463-0202
Fax: (401) 463-3433
Website: www.techaccess-ri.org

Therapeutic Recreation

PLAYGROUNDS

COVENTRY GREENWAY & CROSSTOWN BIKE PATH

Accessible bike path with picnic tables, in-line skating, cross country skiing, hiking paths, horseback riding, bike paths.

GLOCESTER MEMORIAL PARK

Adelaide Rd., Chepachet. Accessible playground and other recreation facilities, including basketball courts, baseball fields and tennis courts.

HANAFORD SCHOOL

LeBaron Drive, East Greenwich. Accessible, large, community-built playground with Kids Kastle.

HASBRO BOUNDLESS PLAYGROUND

At Hasbro Boundless Playground at Roger Williams Park in Providence, (401) 727-5931. Children with physical disabilities can enjoy at least 70% of the play activities without having to leave their support equipment behind. Equally important, the equipment is designed to be sensory rich and developmentally appropriate, so children with all types of abilities can laugh, play, and grow together. There is also a 3,500 square foot sensory garden that houses over 500 plants. Visitors will learn about horticulture and the natural world through plants that have different textures, scents and colors.

HERBERT F. PAYNE MEMORIAL PARK

1277 Main St., Coventry. Accessible park with picnic tables, basketball courts, baseball fields, in-line skating, tennis courts, softball fields, playground, recreation center, concession stands.

imPOSSIBLE DREAM PLAYGROUND

575 Centerville Road, Warwick, (401) 823-5566. Kids can be a train engineer, castle dweller, backhoe operator and more, in addition to enjoying the variety of contraptions to swing, climb or ride on. There's even mini-golf. The site is owned by the imPossible Dream, a non-profit organization devoted to granting dreams to chronically ill or needy children in Rhode Island. The playground also has on-site restrooms. Open daily, 10:00 am- to 3:00 pm, except holidays and holiday weekends. A \$1 donation per child is suggested; train rides cost 50 cents and are offered Monday-Friday at 11:30 am and 1:30 pm.

INDIA POINT PARK

India Ct., Providence. Accessible waterfront park, picnic tables, in-line skating, sledding, bike paths, community boating.

JAMESTOWN COMMUNITY PLAYGROUND

26 North Main Road, Jamestown. Accessible playground (made entirely from recycled materials). Special features include a clatter bridge, the SS Jamestown boat, a sea monster and picnic tables.

MATTY'S PLACE

A new accessible playground at Hazard School on Columbia Street in Wakefield. Designed by Kompan, Inc., the playground features modern apparatus accessible for those with special needs, and a rubber-based ground cover to ensure safety. It is named in memory of five-year-old Matthew Siravo who had epilepsy and many special needs throughout his five years of life. Matty died unexpectedly on Mother's Day in 2003.

PECK CENTER PLAYGROUND

Country Rd., Barrington (behind Barrington Town Hall). Large wooden and accessible playground.

THE SARAH JANE MCCULLOUGH HANDICAPPED PLAY AREA

Scheduled for ground breaking this Spring at Crandall Field, off Main Street (Route 3) in Hopkinton. Named in memory of Sarah Jane McCullough who was born with a disability that confined her to a wheelchair. Sarah Jane died in March, 2003.

SOUTH KINGSTOWN TOWN BEACH

Matunuck Beach Rd., S. Kingstown, (401) 789-9301. Accessible beach with picnic area, playground, restrooms, swimming, volleyball, walking paths.

TIVERTON TOWN RECREATIONAL AREA

Main Road, South Tiverton. Accessible sandy playground for all ages, has tennis, baseball fields, soccer fields.

TUCKERTOWN PARK

Tuckertown, Rd., S. Kingstown. (401) 789-9301. Accessible park (65 acres) with baseball fields, soccer fields, basketball courts, tennis courts, nature trails, picnic area, playground, restrooms and tennis courts.

WEST KINGSTOWN PARK

Rt. 138, West Kingstown, (401) 789-9301. Accessible park, 12 acres with basketball, picnic area, playground, restrooms, softball, tennis, volleyball, walking paths.

OTHER ACTIVITIES AND PROGRAMS

CHALLENGED ATHLETES FOUNDATION

Challenged Athletes Foundation helps pay for a number of different needs, including adaptive equipment and training, so that people with disabilities can get involved in organized sports or just go to summer camp. Call for details.

2148-B Jimmy Durante Blvd, Del Mar, CA 92014

Phone: (858) 793-9293

Website: www.challengedathletes.org

THE CHILDREN'S PHYSICAL DEVELOPMENTAL CENTER

The Children's Physical Developmental Center is a unique physical, motor and recreation program that has been serving children with disabilities from Eastern Massachusetts and Rhode Island since January 1974. The program is designed to enhance perceptual-motor, gross motor, sport, aquatic and leisure skills, as well as social development of children and youth with disabilities, ages 18 months to 18 years. Fifty-five children attend the program in two eight-week sessions during the fall semester and the spring semester each academic year. Over 100 undergraduate and graduate students from 12 academic majors serve as clinicians and group leaders in the program. The clinic is held at the John J. Kelly Gymnasium on the campus of Bridgewater State College. The clinic uses the Olympic size swimming pool, two gymnasiums, an early childhood intervention center and a physical fitness training room.

Kelly Gymnasium Rm 107,

Bridgewater State College, Bridgewater, MA 02325

Phone: (508) 531-1776.

Website: www.bridgew.edu/cpdc

FIRST SWING RHODE ISLAND

First Swing Rhode Island conducts golf clinics for people with disabilities and instructional clinics for therapists. Participants with disabilities work with trained rehabilitation, PGA and recreational professionals under the expertise of First Swing RI instructors to learn how to swing a golf club using an adaptive golf cart for seated individuals and/or adaptive golf clubs and equipment.

Phone: (401) 294-4210

Website: www.firstswingri.org

GREENLOCK THERAPEUTIC RIDING CENTER

The Greenlock Therapeutic Riding Center offers hippo therapy for children with disabilities including autism. Horseback riding for people of all ages with physical, developmental, or emotional disabilities. It is a place where 130 riders, with all types of disabilities, come six days a week to sit on the Greenlock horses to strengthen their legs, to teach their bodies to balance, or to learn to hold their head up by themselves. A horse serves as a bridge to a world that may, until now, have been inaccessible. Each session is geared to the individual and can be flexible depending on the rider's needs. Sessions are conducted by certified riding instructors; hippotherapy component by licensed physical, occupational and speech therapists. The Greenlock Riding Center does accept Medical Assistance and other forms of insurance.

55 Summer Street, Rehoboth, MA 02769

Phone: (508) 252- 5814

Website: www.greenlock.org

RHODE ISLAND FAMILY GUIDE—SUMMER CAMP DIRECTORY

The Rhode Island Family Guide is published three times a year and is free to all families. Each resource guide contains comprehensive information on the following topics: entertainment, health care, education, camps and alternative methods to good health.

PO Box 163, Warren, RI 02885

Phone: (401) 247- 0850

Fax: (401) 247- 0850

Website: www.rifamilyguide.com

SHAKE A LEG

Shake a Leg provides mainstream, complimentary, and recreational therapeutic services (including adaptive sailing program) that develop independent living skills for individuals who have experienced spinal cord injury and related nervous system disorders.

PO Box 1264, Newport, RI 02840

Phone: (401) 849-8898

Fax: (401) 848-9072

Website: www.shakealeg.org

SPECIAL OLYMPICS

Year-round training and competition in Olympic-type sports for children and adults with mental retardation and/or closely-related developmental disabilities. Unified Sports teams up athletes with cognitive disabilities and those without for bowling, basketball, soccer, softball, volleyball, sailing and golf. The Motor Activities Training Program provides comprehensive motor activity and recreation training for people with significant developmental disabilities. Athletic Leadership programs are “off the field” initiatives involving athletes at all levels including Officials Programs for Athletes, Sargent Shriver Global Messengers Program and Athletes Congresses.

33 College Hill Road, Warwick, RI 02886

Phone: (401) 823-7411

Fax: (401) 823-7415

Website: www.specialolympics.org

VSA RHODE ISLAND

VSA Arts of Rhode Island is a statewide non-profit organization providing high quality programs and opportunities for people with disabilities to actively participate in the visual, literary, and performing arts.

500 Prospect Street, Pawtucket, RI 02860

Phone: (401) 725-0247

Fax: (401) 725-0397

TTY: (800) 745-5555

Website: ri.vsarts.org

The Cracked Pot

The following story, “The Cracked Pot,” is by an unknown author and shares the message that all children are a special gift.

A water bearer in India had two large water pots. They hung on opposite ends of a pole, which he carried across his neck. One of the pots had a crack in it and while the other pot was perfect and always delivered a full portion of water at the end of the long walk from the stream to the master’s house, the cracked pot always arrived only half full.

For a full two years this went on daily, with the water bearer delivering only one and a half pots full of water in his master’s house. Of course, the perfect pot was proud of its accomplishments, perfect to the end for which it was made. But the poor cracked pot was ashamed of its imperfection, miserable that it could accomplish only half of what it had been made to do.

After two years of what it perceived to be a bitter failure, it spoke to the water bearer one day by the stream. “I am ashamed of myself and I want to apologize to you.”

“Why?” asked the water bearer. “What are you ashamed of?”

“I have been able, for these past two years, to deliver only half my load because this crack in my side causes water to leak out all the way back to your master’s house. Because of my flaws, you have to do all of this work and you don’t get full value from your efforts,” the pot said.

The water bearer felt sorry for the old cracked pot and in his compassion he said, “As we return to the master’s house, I want you to notice the beautiful flowers along the path.”

Indeed, as they went up the hill, the cracked pot took notice of the sun warming beautiful flowers on the side of the path and this cheered it. But at the end of the trail, it still felt bad because it had leaked out half its load, and so again it apologized to the water bearer for its failure.

The water bearer said to the pot, “Did you notice that there were flowers only on your side of the path, but not on the other pot’s side? That’s because I have always known about your flaw and I took advantage of it. I planted flower seeds on your side of the path and everyday while we have walked back from the stream, you’ve watered them. For two years I have been able to pick these beautiful flowers to decorate my master’s table. Without you being just the way you are, he would not have this beauty to grace his house.”

MORAL: Each of us has our own unique flaws. We’re all cracked pots. But it’s the cracks and flaws we each have that make our lives together so very interesting and rewarding. We need to take each person for what they are and look for the good in them. There is a lot of good out there. Every day we look in the mirror we can wonder what flowers we’ll unknowingly be watering that day.

Alternative Education Placements

Note: See Section 5 of this guide for more information on Alternative Education Placement.

BARRINGTON

St. Andrew's School

63 Federal Road
Barrington, RI 02806
Grades: 6-12
Phone: (401) 246-1230
Fax: (401) 246-0510

CRANSTON

Cornerstone School

665 Dyer Avenue
Cranston, RI 02920
Grades: PreK-12
Phone: (401) 942-2388
Fax: (401) 944-7480

NFI/ACE Program

735 New London Avenue
Cranston, RI 02920
Grades: 7-11
Phone: (401) 946-2020
Fax: (401) 946-2032

Valley Community School

83 Rolfe Square
Cranston, RI 02910
Grades: K-12
Phone: (401) 941-9707
Fax: (401) 785-2517

EAST PROVIDENCE

Bradley Hospital

Developmental Disabilities Program Day School
1011 Veterans Memorial parkway
East providence, RI 02915
Grades: K-12
Phone: (401) 432-1000
Fax: (401) 432-1500

Bradley School

1011 Veterans Memorial Parkway
East Providence, RI 02915
Grades: K-12
Phone: (401) 432-1411
Fax: (401) 432-1224

Meeting Street School

667 Waterman Avenue
East Providence, RI 02914
Grades: PreK-12
Phone: (401) 438-9500
Fax: (401) 438-3760

GLOCESTER

Harmony Hill School, Inc.

63 Harmony Hill Road
Chepachet, RI 02814
Phone: (401) 949-0690
Fax: (401) 949-4419

LINCOLN

The Spurwink School

365 River Road
Lincoln, RI 02865
Grades: K-12
Phone: (401) 781-4380
Fax: (401) 334-3783

MIDDLETOWN

Valley Community Center

60 Hammarlund Way
Middletown, RI 02842
Phone: (401) 849-7452
Fax: (401) 849-8021

NARRAGANSETT

Ocean Tides, Inc.

635 Ocean Road
Narragansett, RI 02882
Grades: 7-12
Phone: (401) 789-1016
Fax: (401) 788-0924

NEWPORT

James L. Maher School

120 Hillside Avenue
Newport, RI 02840
Grades: K-12
Phone: (401) 846-3518
Fax: (401) 847-9459

SOUTH KINGSTOWN

Valley Community School

2299 Tower Hill Road
Saunderstown, RI 02874
Grades: K-12
Phone: (401) 295-9021
Fax: (401) 295-9940

NORTH PROVIDENCE

St. Mary's Home for Children George N. Hunt Campus School

440 Fruit Hill Avenue
North Providence, RI 02911
Grades: 1-12
Phone: (401) 353-3900 x 311
Fax: (401) 353-0984

PAWTUCKET

The Tides School

242 Dexter Street
Pawtucket, RI 02860
Grades: 6-12
Phone: (401) 742-8060
Fax: (401) 724-8899

Valley Community School

249 Roosevelt Avenue
Pawtucket, RI 02860
Grades: K-12
Phone: (401) 722-3513
Fax: (401) 722-1815

PORTSMOUTH

The Bradley School

2820 East Main Road
Portsmouth, RI 02871
Grades: K-12
Phone: (401) 682-1816
Fax: (401) 682-1823

PROVIDENCE

Center for Individualized Training and Education

15 Bough Street
Providence, RI 02909
Grades: Pre K-12
Phone: (401) 351-0610
Fax: (401) 351-5510

Mount Pleasant Academy

1246 Chalkstone Avenue
Providence, RI 02908
Grades: Pre K-12
Phone: (401) 521-4335
Fax: (401) 521-2508

North American Family Institute**Alternatives Program**

350 Duncan Drive

Providence, RI 02906

Grades: 7-12

Phone: (401) 453-4740

Fax: (401) 453-2508

Ocean Tides School

260 Highland Avenue

Providence, RI 02906

Grades: 9-12

Phone: (401) 861-3778

Fax: (401) 831-0309

School One

220 University Avenue

Providence, RI 02906- 5434

Grades: 9-12

Phone: (401) 331-2497

Fax: (401) 421-8869

Tavares Educational Center

Tavares Pediatric Center

101 Plain Street

Providence, RI 02903

Grades: Pre K-12

Phone: (401) 273-7899

Fax: (401) 272-4752

The Groden Center

86 Mount Hope Avenue

Providence, RI 02906

Grades: Pre K-12

Phone: (401) 274-6310

Fax: (401) 421-3280

The Providence Center School

520 Hope Street

Providence, RI 02906

Grades: Pre K-12

Phone: (401) 276-4531

Fax: (401) 276-4015

The Tides School

790 Broad Street

Providence, RI 02905

Grades: 9-12

Phone: (401) 467-8228

Fax: (401) 467-8889

Vocational Resources School

Goodwill Industries of RI

100 Houghton Street

Providence, RI 02904

Grades: 9-12

Phone: (401) 861-2080

Fax: (401) 454-0889

Winners Circle

801 Elmwood Avenue

Providence, RI 02907

Grades: 7-12

Phone: (401) 785-8446

SOUTH KINGSTOWN**Bradley School**

4781 Tower Hill Road

Wakefield, RI 02879

Grades: Pre K-12

Phone: (401) 284-1040

Fax: (401) 284-1045

South Shore School

730 Kingstown Road

Wakefield, RI 02879

Grades: K-12

Phone: (401) 783-1150

Fax: (401) 783-2558

Valley Community School

2299 Tower Hill Road

Wakefield, RI 02874

Grades: 5-11

Phone: (401) 295-9021

Fax: (401) 295-9940

WARWICK**Eleanor Briggs School**

116 Long Street

Warwick, RI 02886

Grades: K-12

Phone: (401) 732-1540

Fax: (401) 732-4658

Pathways Strategic Teaching Center of Kent

County Chapter RIARC

3445 Post Road

Warwick, RI 02886

Grades: Pre K-6

Phone: (401) 739-2700

Fax: (401) 737-7899

Sargent Rehabilitation Center

800 Quaker Lane

Warwick, RI 02818

Grades: Pre K-12

Phone: (401) 886-6603

Fax: (401) 886-6632

Shawomet Alternative School

1642 West Shore Road

Warwick, RI 02889

Grades: 6-8

Phone: (401) 732-3722

Fax: (401) 732-3723

WEST WARWICK**The Tides School**

222 Washington Street

West Warwick, RI 02893

Grades: 9-12

Phone: (401) 822-1360

Fax: (401) 823-4694

WOONSOCKET**Action Based Enterprises**

55 Main Street

Woonsocket, RI 02895

Grades: K-12

Phone: (401) 767-5959

Fax: (401) 767-5957

New Pride School/Hillside

115 Ricard Street

Woonsocket, RI 02895

Grades: 9-12

Phone: (401) 762-0769

Fax: (401) 762-0958

Viola M. Berard School

PO Box 1700

Woonsocket, RI 02895- 0856

Grades: K-12

Phone: (401) 235-7430

Fax: (401) 767-9107

State Agencies

RHODE ISLAND DEPARTMENT OF CHILDREN, YOUTH AND FAMILIES (DCYF)

The RI Department of Children, Youth and Family was established by the state in 1980 by merging children's programs previously administered by four different state agencies. DCYF is responsible for promoting and protecting the health, well-being and development of children and their families. The three major service areas provided by the DCYF are child welfare, Children's Behavioral Health and Education, and Juvenile Corrections. There are four regional offices located throughout the state. The main office is located at the address below.

RI Department of Children, Youth and Families
101 Friendship Street, Providence, RI 02903
Phone: (401) 528-3548
Website: www.dcyf.ri.gov

RHODE ISLAND DEPARTMENT OF EDUCATION (RIDE)

The Rhode Island Department of Education's Office of Special Populations is committed to ensuring that children with disabilities are able to be active, productive citizens, life-long learners, and productive workers. RIDE operates a Consumer Complaint program staffed by legal counsel to ensure that Special Education programs comply with federal and state regulations.

Rhode Island Department of Education
Shepard Building, 255 Westminster Street, Providence, RI 02903
Phone: (401) 222-4600
Fax: (401) 222-6030
Website: www.ridoe.net

RHODE ISLAND DEPARTMENT OF HEALTH

The primary mission of the Rhode Island Department of Health is to prevent disease and to protect and promote the health and safety of the people of Rhode Island. The Division of Family Health houses many programs including the Office of Families Raising Children with Special Health Care Needs. Other programs sponsored by the Department of Health include Lead, Immunizations, Women Infants and Children (WIC), and Newborn Screening.

Rhode Island Department of Health
Division of Family Health, 3 Capitol Hill, Providence, RI 02908
Phone: (401) 222-2231
Fax: (401) 222-6548
Website: www.health.ri.gov

RHODE ISLAND DEPARTMENT OF HUMAN SERVICES

The Rhode Island Department of Human Services administers programs and services for children (including children with special health care needs), families, and adults. Programs and services relative to children with special health care needs include: CEDARR, Early Intervention, the Medical Assistance Program, RIte Care, RIte Share, and RIte Smiles.

Center for Child and Family Health
600 New London Ave, Cranston, RI 02920
Phone: (401) 462-5300 (English and Spanish)
Website: www.dhs.ri.gov

RHODE ISLAND DEPARTMENT OF MENTAL HEALTH, RETARDATION AND HOSPITALS

The mission of this Department is to fund, plan, design, develop, administer and coordinate a system of services for identified citizens of Rhode Island with specific disabilities.

Administrative Offices and Substance Abuse
14 Barry Hall, Cranston, RI 02920
Phone: (401) 462-3201
Fax: (401) 462-3204
Website: www.mhrh.state.ri.us/about_our_dept.htm

Division of Developmental Disabilities
Social Service Unit, Simpson Hall, 1st Floor, P.O. Box 20523, Cranston, RI 02920
Phone: (401) 462-3233
Website: www.mhrh.state.ri.us/about_our_dept.htm

GOVERNOR'S COMMISSION ON DISABILITIES

The Commission's goal is to ensure that all people with disabilities are given the opportunities to exercise their rights and responsibilities as Rhode Island citizens and that each person with a disability is able to reach his or her maximum potential in independence, human development, productivity, and self-sufficiency. The Commission is responsible for ensuring state agencies comply with the state and federal disability rights laws. The Commission acts as a mediator in solving disability discrimination complaints and explores options for resolving the complaints.

John O. Pastore Center
41 Cherry Dale Court, Cranston, RI 02920
Phone: (401) 462-0100
TTY: (401) 462-0101
Fax: (401) 462-0106
Website: www.gcd.state.ri.us

Websites

THE AMERICAN ACADEMY OF PEDIATRICS

A report by the American Academy of Pediatrics: The pediatrician's role in the Diagnosis and Management of Autistic Spectrum Disorder in Children.

<http://www.aap.org/policy/re060018.html>

ASPERGER'S ASSOCIATION OF NEW ENGLAND

The Asperger's Association of New England provides families with information on local support groups for children and adults.

http://aane.autistics.org/brochures/CH_Maine.html

ASPERGER COALITION OF THE UNITED STATES

The Asperger Coalition of the United States is a national non-profit organization committed to providing the most up-to-date and comprehensive information on Asperger Disorder and related conditions. They are based in Washington, D.C.

<http://www.asperger.org>

ASPERGER SYNDROME TEENS

A website started by a teen with Asperger who is willing to help other teens who have Asperger Syndrome.

<http://www.aspergerteens.com>

AUTISM ASPERGER RESOURCE CENTER (AARC)

The Purpose of the Autism Asperger Resource Center is to foster the behavioral, academic and social development of persons with Autism, Asperger Disorder, and related exceptionalities by offering a variety of services to individuals and support networks.

<http://www.kumc.edu/aarc/links.html>

AUTISM CONFERENCES

This board is for the public posting of autism related conferences. If you know of a conference that is not listed here, please add it along with a link to the conference site for more information.

<http://www.network54.com/Forum/58400?it=0>

AUTISM: HAND IN HAND

Educational website with collection of programs, learning materials, play activity ideas and more.

<http://www.autismhandinhand.com>

AUTISM NETWORK INTERNATIONAL (ANI)

An autistic run self-help and advocacy group for autistic people.

<http://ani.autistics.org>

AUTISM ONLINE

The mission of Autism Online is to connect the parents of newly diagnosed children with autism and professionals working with these children with critical resources, support, and research information in their own language. This is a commercial site.

<http://www.autismonline.org>

AUTISM—PDD RESOURCES NETWORK

Topics range from research to diagnosis to education (including lists of schools K–12 by state, college preparation and procedure on how to apply), job search, and estate planning.

<http://www.autism-pdd.net>

AUTISM PROJECT OF RHODE ISLAND

The website is updated with training and social group schedules. There are also additional resources for parents and professionals.

<http://www.theautismproject.org>

AUTISM RESEARCH INSTITUTE (ARI)

ARI is primarily devoted to conducting research and to sharing the results of research on the causes of autism and on the methods of preventing, diagnosing, and treating autism and other severe behavioral disorders of childhood. ARI provides information based on research to parents and professionals throughout the world.

<http://www.autismwebsite.com/ari/index.htm>

AUTISM SOCIETY OF AMERICA (ASA)

The Autism Society of America (ASA) is one of the leading organizations in the United States for promoting awareness and developing support for the autism community. The ASA was founded in 1965 by a small group of parents working on a volunteer basis out of their homes, and it has over 20,000 members with nearly 200 chapters.

<http://www.autism-society.org/site/PageServer>

AUTISM SPECTRUM DISORDERS (ASD)

This website offers research and treatments on ASD.

<http://www.cdc.gov/ncbddd/autism/index.htm>

AUTISM TEACHING TOOLS

This site offers practical information about teaching a child who has Autism. It contains an index of over 200 books, songs, games and toys that can assist educators and parents in teaching their child. The goal is to have a source of materials for parents to refer to when teaching a specific cognitive concept or skill. The website welcome comments from parents and professionals who have effective ways to teach a particular skill or concept.

<http://www.autismteachingtools.com>

AUTISTIC ADVOCACY

Articles, editorials and questionable attempts at humor. All content by Frank Klein.

<http://home.att.net/~ascaris1/>

AUTISTICS.ORG

Links autistic people with the services needed to lead a productive life. The goal of the website is to create a global database of information and resources for persons on the autistic spectrum.

<http://www.autistics.org>

CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)

The CDC is one of several agencies that have projects in place to study autism spectrum disorders.

<http://www.cdc.gov/ncbddd/dd/ddautism.htm>

CENTER FOR THE STUDY OF AUTISM (CSA)

CSA is located in the Salem, Portland, Oregon area. The Center provides information about autism to parents and professionals, and conducts research on the efficacy of various therapeutic interventions. Much of CSA's research is in collaboration with the Autism Research Institute in San Diego, California.

<http://www.autism.org/contents.html>

CLINICAL TRIALS: AUTISM

The government provides patients, family members, health care professionals and members of the public with easy access to information on clinical trials for a wide range of diseases and conditions. This site was started in February 200 and currently contains approximately 7,600 clinical studies sponsored by the National Institutes of Health, other federal agencies, and the

pharmaceutical industry in over 89,000 locations worldwide. Studies listed in the database are conducted primarily in the United States and Canada, but include locations in about 80 countries. ClinicalTrials.gov receives over 3 million page views per month and hosts approximately 11,000 visitors daily.

<http://clinicaltrials.gov/ct/gui/action>

CURE AUTISM NOW (CAN)

Cure Autism Now is an organization for parents, physicians, and researchers working to promote understanding about autism and funding research. While the website has a great deal of information on their programs and the fund raising that they are doing, there are a large number of links to other websites and resources that are valuable for people studying autism. The Science Watch section will be of interest to people wishing to view the latest scientific research.

<http://www.cureautismnow.org>

DEFEAT AUTISM NOW (DAN)

A network of practitioners, in partnership with the Autism Research Institute, who use biological and nutritional interventions to try to improve the physical and behavioral symptoms of autism.

<http://www.autismwebsite.com/ari/dan/dan.htm>

THE DOUG FLUTIE JR. FOUNDATION

The Foundation's mission is to aid financially-disadvantaged families that need assistance in caring for their child with autism; to fund education and research into the causes and consequences of childhood autism; and to serve as a clearinghouse and communications center for new programs and services developed for people with autism.

<http://www.dougflutiejrfoundation.org>

FAMILY VILLAGE

A global community that integrates information, resources, and communication opportunities on the Internet for persons with cognitive and other disabilities, for their families, and for those that provide them services.

<http://www.familyvillage.wisc.edu>

THE GRODEN CENTER, INC.,

The Groden Center, Inc., the largest provider in Rhode Island of services dedicated to individuals with ASD, was founded in 1976 with a mission to support, teach, nurture, and challenge individuals with ASDs to reach their greatest level of independence, productivity, and participation in their communities. A variety of programs accomplish this goal by

providing the most effective educational and therapeutic services by advancing knowledge and best practices through research, education, and training, and by involving, educating, and supporting families in caring for and advocating for their children.

<http://www.grodencenter.org>

NATIONAL CENTER ON BIRTH DEFECTS AND DEVELOPMENTAL DISABILITIES

Promotes health, wellness, and quality of life in those with disabilities. Great information on autism spectrum disorders.

Centers of Disease Control and Prevention
4770 Buford Highway (F-35),
Atlanta, GA 30341
Phone: (770) 488-7082
Fax: (770) 488-7075.
<http://www.cdc.gov/ncbddd/dd/ddautism.htm>

NATIONAL DISSEMINATION CENTER FOR CHILDREN WITH DISABILITIES

The National Dissemination Center for Children with Disabilities serves as a central source of information on IDEA, the Nation's special education law; No Child Left Behind as it relates to children with disabilities; and on effective educational practices. Includes a State Resource list for each state, giving helpful contacts and information on Parent Training. Can be contacted by telephone, email, or mail, in English or Spanish.

P.O. Box 1492, Washington, DC 20013
Phone: (800) 695-0285
Fax: (202) 884-8441
Email: nichcy@org
<http://www.nichcy.org>

NATIONAL EARLY CHILDHOOD TECHNICAL ASSISTANCE

Excellent site for information on ASD.

Campus Box 8040, UNC-CH Chapel Hill, NC 27598-8040
Phone: (919) 962-2001
Fax: (919) 966-7463.
<http://www.ectac.org>

NATIONAL INSTITUTE OF CHILD HEALTH AND HUMAN DEVELOPMENTS

A public service website covering many Autism-related topics.

<http://www.nichd.nih.gov/autism/>

NATIONAL INSTITUTE OF MENTAL HEALTH

NIMH scientists are dedicated to understanding the workings and interrelationships of the various regions of the brain and to develop preventative measures and new treatments for autism.

<http://www.nimh.nih.gov/publicat/autism.cfm>

NATIONAL INSTITUTE OF MENTAL HEALTH

Office of Communications

6001 Executive Blvd., Room 8184, MSC 9663, Bethesda, MD 20892-9663

Phone: (301) 443-4513 or (866) 615-6464 toll free

Fax: (301) 443-4279

<http://www.nimh.nih.gov>

NETWORK OF INTERNATIONAL FARM COMMUNITIES (NIFCA)

The Network of International Farm Communities for Autism (NIFCA) is a tremendous organization that promotes efforts “to provide farmstead communities which meet the residential, vocational and recreational needs of the growing population of adults with autism.” The organization was founded in 1974 and has member communities all over the world. The website offers links to many of these organizations, historical and statistical information, and links to other resources.

<http://www.autismnetwork.net>

NEW ENGLAND CENTER FOR CHILDREN

Since its founding in 1975, The New England Center for Children has remained true to its original mission: providing state-of-the-art education and individualized treatment-care and respect for children with autism and other disabilities.

<http://www.necc.org>

O.A.S.I.S.

Online Asperger Syndrome Information and Support. The website is run by parents.

<http://www.udel.edu/bkirby/asperger>

SUBSTANCE ABUSE AND MENTAL HEALTH SERVICES ADMINISTRATION

Mental Health Information Center
PO Box 42557; Washington, DC 20015;
Phone: (800) 789-2647
Fax: (301) 984-8798
<http://www.samhsa.gov/centers/cmhs/cmhs.html>

UNITED STATES FOOD AND DRUG ADMINISTRATION

Information on medications approved by the Food and Drug Administration

5600 Fishers Lane; Rockville, MD 20857-0001
Phone: (888) 463-6332
<http://www.fda.gov>

WRIGHTSLAW.COM

Parents, educators, and attorneys come to Wrightslaw for accurate, up-to-date information about special education law and advocacy for children with disabilities.

<http://www.wrightslaw.com>

THE YALE DEVELOPMENTAL DISABILITIES CLINIC

The Yale Developmental Disabilities Clinic offers comprehensive, multidisciplinary evaluations for children with social disabilities, usually focusing on the issues of diagnosis and intervention. The clinic is located in the Child Study Center at Yale University, in New Haven, CT.

<http://info.med.yale.edu/chldstdy/autism>

Spanish Links

VISION GLOBAL DEL AUTISMO

<http://www.autism.org/translations/spanish.html>

INTERNATIONAL AND NATIONAL AUTISM LINKS

Extensive list of Autism-related links.

<http://www.autism-resources.com/links/organizations.html>

Christopher and Jonathan's Story

The following story, written by Amy, a mother of two children with ASDs, describes the importance of providing her sons with treatment and services. Amy is convinced that her children's success is due to all of her wonderful supports.

My second son Jonathan was the perfect baby. He was happy, smiling all the time...a pure joy to our entire family. He even slept for 5 hours straight his first night home from the hospital! Our first son, Christopher, on the other hand, had always been more difficult from the day he was born. He truly didn't seem ready to face the world outside the womb. He cried all the time, didn't nurse well and pretty much never slept. What we didn't know then was the thing these two very different little people had in common was autism.

My two children, so very different, have both been diagnosed with autism. My first child was older when we discovered it, just past three. As new parents, we panned off all his behaviors and sensitivities to his personality. "He's just over sensitive. He just can't handle new situations, noise, crowds, etc." Even our pediatrician backed us up saying, he was fine. That is until his third year check up. At this time the pediatrician bluntly exclaimed, "Maybe he has autism." We were flabbergasted and shocked, to say the least. And then, after we picked ourselves off the floor, the autism journey began with doctors, diagnosis, therapists, the public school system's Special Ed department, etc.

I'm pleased to say my oldest is doing very well. He's a happy, funny little seven-year old. He still has many sensitivities and issues, but he has a lot of great strengths too, like his amazing imagination and great sense of humor. I truly believe he will survive in this world and maybe some day move off this vast spectrum of autism and just be an adult who's a bit on the quirky side.

The jury is still out on my second child, Jonathan. The language and skills that he had as a 15 month old slowly disappeared. Now, at age four he seems to be finally climbing back up and making some progress with the help of picture exchange and a lot services from his wonderful teachers and therapists.

We knew Jonathan had a problem early on and he received extensive services, but his journey seems a bit tougher to me. Maybe it's just harder for us to see a child so sweet have to struggle so much just to communicate with the people who love him. Still, I have hope for him as well.

All I know is that we can't give up on these little guys or stop trying to figure out how this happens. I do believe services and interventions are key to helping them. And, I'm so glad we have the services and therapies to work with them to communicate and be happier children. The one thing I do know is that I love my kids, and the diagnosis of autism will not change that!

Frequent Family Questions

QUESTIONS ANSWERED BELOW:

GENERAL:

- » How common are Autism Spectrum Disorders (ASDs)?
- » Is Asperger Disorder a form of an ASD?
- » What is the difference between Autism and PDD or PDD-NOS?
- » What are the characteristics that define a diagnosis of PDD or an ASD?
- » Are there common concerns or early signs noted by parents that eventually lead to an ASD diagnosis?
- » At what age can an ASD be diagnosed?

OBTAINING A DIAGNOSIS:

- » If my child is really delayed in some way, how will I know, and can't we just wait and see if he or she grows out of it?
- » My child can talk, but his teacher still thinks he or she has an ASD. How can I be sure?
- » My child is three and not talking yet, does this mean he or she has an ASD?
- » How can my child be assessed if he/she cannot talk?

AFTER DIAGNOSIS:

- » What is the prognosis for my child with an ASD?
- » What about medication for my child with an ASD?
- » When should teachers begin to offer vocational instruction?
- » Can students with an ASD be included in the general education setting?

GENERAL

HOW COMMON ARE AUTISM SPECTRUM DISORDERS?

It is estimated that 1 in 166 children born in the U.S. today have an Autism Spectrum Disorder or some form of pervasive developmental disorder. Its prevalence makes ASDs one of the most common developmental disabilities. ASDs are more common in boys than girls.

IS ASPERGER DISORDER A FORM OF AN ASD?

Yes. Asperger Disorder is an ASD that affects the way a person communicates and relates to others. People with Asperger Disorder generally have language skills, are “high functioning,” and are of average or above average intelligence. Concrete and literal thinking and an obsession—or extremely narrow interest—often characterize this disorder. Children with Asperger Disorder may not receive a diagnosis immediately, since they frequently develop speech at an average rate.

WHAT IS THE DIFFERENCE BETWEEN AUTISM AND PDD OR PDD-NOS?

The Pervasive Developmental Disorders are a group of disorders including Classic Autism, Childhood Disintegrative Disorder, Rett’s Syndrome, Pervasive Development Disorder, Pervasive Development Disorder – Not Otherwise Specified, Asperger Disorder. They are also known as Autism Spectrum Disorders. A person’s diagnosis is determined based upon evaluation of criteria such as which areas are impacted and how strongly the area is impacted. PDD-NOS is a milder or atypical Autism Spectrum Disorder.

WHAT ARE THE CHARACTERISTICS THAT DEFINE A DIAGNOSIS OF AN ASD?

The characteristics required for a diagnosis of any ASD are listed in The Diagnostic and Statistical Manual of the American Psychological Association. The three major characteristics are: problems in communication or use of verbal language, poor social skills, and a restricted range of interests and repetitive behaviors.



ARE THERE COMMON CONCERNS OR EARLY SIGNS NOTED BY PARENTS THAT EVENTUALLY LED TO AN ASD DIAGNOSIS?

There are common concerns expressed by parents and pediatricians prior to the diagnosis of an ASD. Some of them include, but are not limited to:

1. Lack of speech and/or had words and lost them.
2. Child speaks extremely well for a three year old, but can't play, imitate, and has tantrums.
3. Child appears to be deaf; does not answer when called or react to loud noises.
4. Child does not make eye contact with parent/caregiver.
5. Child does not comment about or notice surroundings.
6. Child has unusual, odd behaviors including severe tantrums, self-injurious behavior, is difficult to control, engages in self-stimulatory behaviors (e.g., flapping, rocking, spinning), and has no concept of danger.
7. Child ignores or does not play with other children.

AT WHAT AGE CAN AN ASD BE DIAGNOSED?

Children are now being evaluated and diagnosed at an earlier age, many as early as 16 months of age.

OBTAINING A DIAGNOSIS

IF MY CHILD IS REALLY DELAYED IN SOME WAY, HOW WILL I KNOW, AND CAN'T WE JUST WAIT AND SEE IF HE/SHE GROWS OUT OF IT?

First, trust your instincts and tell your concerns to your doctor. Your doctor can assess if your child is reaching the appropriate developmental milestones and, if needed, refer your child for further evaluation. Families can also access the Early Intervention Program for an assessment if they have any concerns regarding their child's development. Early Intervention services are available in every state for children ages birth to three years old.

It's important for families not to take a "wait and see" approach regarding their child's development. Research shows that early intervention is key to improving developmental delays—including ASDs. A good resource for early signs is the campaign "Learn the Signs. Act Early." developed by the U.S. Centers for Disease Control and Prevention (CDC). For more information, visit the CDC website at www.cdc.gov/actearly.

MY CHILD CAN TALK, BUT HIS TEACHER STILL THINKS HE/SHE HAS AN ASD.

HOW CAN I BE SURE?

Many children and adults with an ASD do talk! To know for sure if your child has an ASD, find a developmental pediatrician, a psychiatrist, or psychologist specializing in children. Only these professionals are clinically trained to diagnose any form of an ASD.

MY CHILD IS THREE AND NOT TALKING YET, DOES THIS MEAN HE/SHE HAS AN ASD?

No! There are many different reasons to explain why a three year old isn't talking. The first step to an answer is to discuss your concerns with your pediatrician. Consider getting your child's hearing and vision tested to rule out these as a factor in his or her delay. After a pediatrician does a screening, you will have important information to use in deciding if your child needs further evaluation from a developmental pediatrician or other professional.

HOW CAN MY CHILD BE ASSESSED IF HE/SHE CANNOT TALK?

Language or the ability to communicate is only one area of an evaluation. Within that part of the evaluation, the clinician looks at a child's ability to communicate. This includes a wide range of non-verbal skills and developmental milestones. This is why it's important to have an evaluation completed by a licensed team of professionals with experience working with and evaluating individuals with an ASD.

AFTER DIAGNOSIS

WHAT IS THE PROGNOSIS FOR MY CHILD WITH AN ASD?

It is impossible to make a generalization about how any individual child will grow and progress. All children continue to develop, despite delays. What we do know is how early the intervention begins and the quality of programming are key factors to a child's improved development. Today, a child diagnosed with an ASD will receive different interventions beginning at an earlier age than was possible many years ago. This means each child's chances for improving communication and life skills are greater today than years ago.

WHAT ABOUT MEDICATION FOR MY CHILD WITH AN ASD?

There is no medication specifically prescribed for individuals with a diagnosis of an ASD. That said, there are medications that can be prescribed to treat related symptoms and co-existing conditions.

WHEN SHOULD TEACHERS BEGIN TO OFFER VOCATIONAL INSTRUCTION?

With the parents' permission, teachers should introduce basic vocational skills in elementary school, and then slowly build on these skills throughout middle school and high school.

According to the Autism Society of America, teachers should help their students with an ASD to develop vocational and community living skills at the earliest age possible. These skills help children develop independence, become participating members of their communities, and provide the opportunity for students to make more choices about their daily lives.

CAN STUDENTS WITH AN ASD BE INCLUDED IN THE GENERAL EDUCATION SETTING?

Absolutely! It is important to work with your team at school to determine when, where, and for how long your child will be included in the regular education setting. Researchers are currently studying the impact of inclusive settings on students with ASDs, and most educators agree that students with ASDs can benefit from regular interaction with their peers.

The challenge for educators is to identify appropriate methods of providing individualized education programs to children with disabilities in regular education classrooms. “Those involved with children with autism must be concerned that the enthusiasm for integrated placements not take precedence over the more important goal of appropriate education” (Koegel and Koegel, 1996). This means that each child needs to be continually assessed to evaluate whether the inclusion setting is appropriate and that the child continues to be an active participant and learner in the setting. Sitting to the side with an aide doing separate, not-adapted, work is not a good inclusion model.



Important Laws Affecting Individuals with Disabilities

Several laws, amendments, and regulations are designed to protect the rights of people with disabilities in education, work, and daily life in the community. The laws vary in their scope and implementation. A brief description of the laws is listed below, along with web links to access the actual legislation.

SECTION 504 OF THE REHABILITATION ACT OF 1973

This law was the first federal civil rights law to protect people with disabilities. Its language is very similar to other civil rights legislation applying to discrimination on the basis of sex or race. The Law “establishes a mandate to end discrimination and to bring handicapped persons into the mainstream of American life.” It provides that: No otherwise qualified handicapped person shall, on the basis of handicap, be excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any program or activity, which receives or benefits from Federal financial assistance.

Not only does Section 504 prohibit discrimination in work, and accommodation, it provides protection to disabled people in education. Qualifying children are entitled to a free and public education under Section 504 and are protected from discrimination or retaliation in the educational setting. Likewise, Section 504 protects disabled individuals from discrimination in public higher education institutions.

The Statute, 29 U.S.C. Section 794, can be found at <http://caselaw.lp.findlaw.com/cascode/uscodes/29/chapters/16/subchapters/v/sections/section794.html>.

The Final Regulations. 34 C.F.R. Section 104, can be found at <http://www.ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html>.

THE AMERICAN WITH DISABILITY ACT (ADA)

The ADA was signed into law in 1990. The ADA is similar to Section 504 of the Rehabilitation Act of 1973 and extends civil rights protection to persons with disabilities in private sector employment, public services, public accommodation, transportation, and telecommunications. Under ADA, a person with a disability is one who: 1) has a mental or physical impairment that substantially limits that person in a major life activity; 2) has a record of such an impairment; and 3) who is regarded as having such an impairment. Though the law was enacted in 1990, not all parts went into effect at the same time; specific requirements are still being clarified.

The Federal Regulations, 35 C.F.R. 35-101 et seq., can be found at <http://www.ed.gov/policy/rights/reg/ocr/edlite-28cfr35.html>.

INDIVIDUALS WITH DISABILITIES EDUCATION ACT (IDEA)

The IDEA provides that States, through local public school systems, must provide all eligible disabled students with a free and appropriate public education, in the least restrictive environment possible from 3 years old until the end of the 21st year. The IDEA also requires services for infants and toddlers with disabilities.

The law was first enacted in 1970 and substantially revised in 1997 and again in 2004. The IDEA provides significant procedural and substantive rights to disabled children and their parents and serves as the primary source of guidance on the education of disabled students. Under the Act, a child is guaranteed the right to participate in the regular education environment, unless after the full use of supplementary aids and services, he/she is unable to make meaningful progress. The IDEA requires that an Individualized Education Program (IEP) be developed for each eligible disabled child for use as a blueprint for the child's program each year. In addition, numerous provisions secure the parents' rights to meaningfully participate in all aspects of decision making for their child's program. IDEA, 20 U.S.C. Section 1400 et seq., and the Federal regulations, 34 C.F.R. Section 300 et seq., can be found at IDEA Practices, a website maintained by the Council for Exceptional Children and the U.S. Department of Education at <http://www.ideapractices.org/law/index.php>.

The Office of Special Education and Rehabilitative Services (OSEP), a division of the U.S. Department of Education, maintains a website very useful to families. In addition, the site lists policy letters that OSEP has issued on various special education topics. The website can be accessed at <http://www.ed.gov/about/offices/list/osers>. Several private websites contain information helpful to families of disabled students. These include Wrightslaw at <http://www.wrightslaw.com/>, and Reed Martin's website at <http://www.reedmartin.com>.

IDEA INDIVIDUALS WITH DISABILITIES IMPROVEMENT ACT OF 2004

On December 3, 2004, President Bush signed into law, Public Law 108-446, the Individuals with Disabilities Education Improvement Act.

This law affects 6.7 million children with disabilities in public schools across the U.S. The new law is very similar to the No Child Left Behind Act and requires accountability for all students regardless of their abilities. A summary of some of the most critical changes affecting children with disabilities and their families in IDEA 2004 can be found at www.nationalparentcenters.org/idea/letter.htm. The complete bill can be downloaded from www.nationalparentcenters.org/idea/index.htm.

WORK INCENTIVES IMPROVEMENT ACT OF 1999

An important piece of legislation passed Congress in 1999, designed to remove legislative barriers and to provide legislative incentives for people with disabilities to work. This bill, called the Work Incentives Improvement Act of 1999 (S.331), is “to amend the Social Security Act to expand the availability of health care coverage for working individuals with disabilities, to establish a Ticket to Work and Self-Sufficiency program in the Social Security Administration to provide such individuals with meaningful opportunities to work, and other purposes.” Section 331 will:

- » Expand State options under Medicaid for workers with disabilities.
- » Continue Medicaid coverage for working individuals with disabilities.
- » Establish grants to develop and implement state infrastructures to support working individuals with disabilities.
- » Demonstrate coverage of workers with potentially severe disabilities.
- » Establish Ticket To Work and Self-Sufficiency Program.
- » Prohibit the use of work activity as a basis for review of an individual’s disabled status.
- » Establish state grants for work incentives assistance to disabled beneficiaries.
- » Establish demonstration project providing for reductions in disability insurance benefits base earnings.
- » Expedite eligibility determinations for applications of former long-term beneficiaries that completed an extended period of eligibility.

The Act may be found at <http://caselaw.lp.findlaw.com/cascode/uscodes/42/chapters/7/subchapters/xi/parts/a/toc.html>.

Diagnostic Criteria

Many families are curious how physicians diagnose their child with an Autism Spectrum Disorder (ASD). The following are the actual diagnostic criteria that doctors and other professionals use when evaluating children on the Spectrum.

Please note that the numbers to the left of the diagnosis are the DSM–IV codes that are used by professionals and insurance companies to identify the disorder that a child may have.

299.00 AUTISTIC DISORDER

DIAGNOSTIC CRITERIA

- A. A total of six or more items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):
- (1) Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (a) Marked impairment in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction.
 - (b) Failure to develop peer relationships appropriate to developmental level.
 - (c) Lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (for example, lack of showing, bringing, or pointing to objects of interest).
 - (d) Lack of social or emotional reciprocity.
 - (2) Qualitative impairments in communication as manifested by at least one of the following:
 - (a) Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
 - (b) In individuals with speech, marked impairment in the ability to initiate or sustain a conversation with others.
 - (c) Stereotyped and repetitive use of language or idiosyncratic language.
 - (d) Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

- (3) Restricted repetitive and stereotyped patterns of behavior, interest, and activities, as manifested by at least one of the following:
 - (a) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
 - (b) Apparently inflexible adherence to specific, nonfunctional routine or rituals.
 - (c) Stereotyped and repetitive motor mannerisms (for example, hand or finger flapping or twisting).
 - (d) Persistent preoccupation with parts of objects.
- B. Delays or abnormal functioning in at least one of the following areas: with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

299.80 ASPERGER DISORDER

DIAGNOSTIC CRITERIA

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
 - (1) Marked impairment in the use of multiple nonverbal behaviors such as eye-to eye gaze, facial expression, body postures, and gestures to regulate social interaction.
 - (2) Failure to develop peer relationships appropriate to developmental level.
 - (3) A lack of spontaneous seeking to share enjoyment, interests or achievements with other people (for example, a lack of showing, bringing, or pointing out objects of interest to other people).
 - (4) Lack of social or emotional reciprocity.
- B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
 - (1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
 - (2) Apparently inflexible adherence to specific, nonfunctional routines or rituals.
 - (3) Stereotyped and repetitive motor mannerisms (for example, hand or finger flapping or twisting).
 - (4) Persistent preoccupation with parts of objects.
- C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.
- D. There is no clinically significant general delay in language (for example, single words used by age 2 years, communicative phrases used by age 3 years).

- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate, self-help skills, adaptive behavior, and curiosity about the environment in childhood.

299.80 PERVASIVE DEVELOPMENTAL DISORDER— NOT OTHERWISE SPECIFIED (PDD-NOS)

DIAGNOSTIC CRITERIA

- A. PDD-NOS is a form of “atypical autism” where a child may present with symptoms that do not fit the criteria for Autistic Disorder because of the late age of onset and/or atypical symptoms.
- B. PDD-NOS should be used when there is a severe and pervasive impairment in development of reciprocal social interaction or verbal and nonverbal communication skills, or when the atypical symptoms identified in social relationships, social communication, and imaginative play or thought are present.

299.10 CHILDHOOD DISINTEGRATIVE DISORDER

DIAGNOSTIC CRITERIA

- A. Apparently normal development for at least the first 2 years after birth as manifested by the presence of age-appropriate verbal and nonverbal communication, social relationships, play, and adaptive behavior.
- B. Clinically significant loss of previously acquired skills (before age 10 years) in at least two of the following areas:
 - (1) Expressive or receptive language.
 - (2) Social skills or adaptive behavior.
 - (3) Bowel or bladder control.
 - (4) Play.
 - (5) Motor skills.
- C. Abnormalities of functioning in at least two of the following areas:
 - (1) Qualitative impairment in social interaction (for example, impairment in nonverbal behaviors, failure to develop peer relationships, lack of social or emotional reciprocity).
 - (2) Qualitative impairments in communication (for example, delay or lack of spoken language, inability to initiate or sustain a conversation, stereotyped and repetitive use of language, lack of varied make-believe play).
 - (3) Restricted, repetitive, and stereotyped patterns of behavior, interests, and activities, including motor stereotypes and mannerisms.

299.80 RETT SYNDROME

DIAGNOSTIC CRITERIA

A. All of the following:

- (1) Apparently normal prenatal (before birth) and perinatal (after birth) development.
- (2) Apparently normal psychomotor development through the first 5 months after birth.
- (3) Normal head circumference at birth.

B. Onset of all of the following after the period of normal development:

- (1) Deceleration of head growth between ages 5 and 48 months.
- (2) Loss of previously acquired purposeful hand skills between ages 5 and 30 months with the subsequent development of stereotyped hand movements (for example, hand-wringing or hand washing).
- (3) Loss of social engagement early in the course (although often social interaction develops later).
- (4) Appearance of poorly coordinated gait or trunk movements.
- (5) Severely impaired expressive and receptive language development with severe psychomotor retardation.

Glossary

504 PLAN

An education plan developed for a student who does not meet the eligibility for special education services but requires modifications to his or her educational program to promote school success.

ALLERGY

A condition in which the body has an exaggerated response to a substance (e.g., food or drug).

APRAXIA

A speech condition where individuals have difficulty with oral motor planning.

ANGELMAN SYNDROME

A diagnosis confirmed by a specific genetic test, characterized by hand flapping, little or no speech, attention deficits, hyperactivity, and delays in motor development.

ANXIETY DISORDERS

Disorders often characterized by an intense apprehension or fear and distress that can be accompanied by anxiety episodes that can occur in various settings.

ATTENTION DEFICIT DISORDER (ADD)

A neurological disorder characterized by impulsivity and short attention.

ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD)

A neurological disorder characterized by impulsivity, short attention span, and hyperactivity.

ATYPICAL

An aspect of behavior that is not representative of what is thought of as in the range of normative or usual for individuals.

AUDIOLOGIST

A licensed professional who assesses and treats hearing impairments.

BIPOLAR DISORDER

A disorder that is marked by extreme changes in mood, thought, energy, and behavior. This disorder is also known as Manic Depression.

COMMUNICATION

A process by which information is exchanged between two or more individuals through a common system of words, symbols, signs, or behaviors.

CHROMOSOME

Components in a cell, occurring in pairs—one from the mother, the other from the father—that contain genetic information.

CUE

An action on the part of one person that indicates to the other that they should begin a specific action.

DEVELOPMENTAL DELAYS

The lack of development by a certain age of basic skills such as walking, talking etc.

DEVELOPMENTAL/BEHAVIORAL PEDIATRICIAN

A doctor specializing in the care of children and specifically trained to focus on development and behavior.

DIAGNOSIS

The process of identifying a disease or condition by its signs, symptoms and results of various diagnostic procedures.

DEFICIT

Difficulties in intellectual skills, language abilities, social skills, adaptive abilities and other skills that can be developmental or may reflect a loss of abilities.

DETERIORATION

A worsening of deficits or impairments over time.

DEVELOPMENTAL MILESTONES

A set of functional skills or age-specific tasks that most children can do at a certain age range.

DNA

The molecule that contains genetic information in the nucleus of cells that determines the structure, function, and behavior of the cell.

EARLY INTERVENTION

Program provides services to eligible children with developmental delays birth to three years of age. Services include complete developmental testing, in-home support, diagnosis specific services, and links to community services and resources.

EPILEPSY

A chronic disorder characterized by recurrent unprovoked seizures.

FRAGILE X SYNDROME

Fragile X Syndrome (FXS) is the most common cause of genetically-inherited mental impairment that can range from subtle learning disabilities to severe intellectual challenges.

GASTROENTEROLOGIST

A doctor that specializes in digestive disease and disorders.

GENETIC

A term relating to genes or inherited characteristics.

GENETIC DISORDER

A condition that is passed from one family member to the next.

GENETICIST

A doctor who specializes in conditions that are passed from one family member to the next.

GESTURE

A movement of the body or a part of the body used to communicate with others (i.e., to express an idea or emotion).

HORMONE

A chemical substance secreted into body fluids and transported to another organ that produces a specific effect such as altering metabolism or modifying the functioning of the organ.

HYPERACTIVE

A state or tendency to be overly active or excitable.

HYPERLEXIA

A syndrome observed in children who have an amazing ability to read words, Numbers, or letters, but usually with limited comprehension.

INDIVIDUALIZED EDUCATION PROGRAM (IEP)

A written plan developed and agreed upon by the student's parent(s) and the school system to identify services that the school system is required to provide to accommodate the child's needs.

INDIVIDUALIZED FAMILY SERVICE PLAN (IFSP)

A written plan for services developed by an Early Intervention team based on the result of an evaluation or assessment and the concerns of the family.

LEARNING DISABILITY

Any condition that interferes with an individual's ability to learn, thought to be caused by difficulties in processing and integrating information.

MANNERISMS

An idiosyncrasy of behavior that is specific or distinctive of an individual.

MENTAL RETARDATION (MR)

Significant delays in intellectual skills and adaptive functioning as evaluated by the use of IQ tests and assessments of individuals' independent and self-help skills.

MOTOR CONTROL

The ability to regulate and direct purposeful movements of the body, including fine motor control of the hands and fingers as well as gross motor control of large movements and posture.

NATURAL ENVIRONMENTS

Natural Environments are the day-to-day settings, routines, and activities that young children learn best in.

NEUROLOGICAL CONDITION

A condition of the nervous system especially in respect to its structure, functions, and abnormalities.

NEUROLOGIST

A medical doctor who specializes in the diagnosis and treatment of disorders of the nervous system.

NONVERBAL LEARNING DISORDERS (NLD)

A disorder that is neurological in origin and affects a child's ability to organize visual and spatial information, adapt to new social settings, and/or accurately read nonverbal cues.

OBSESSIVE COMPULSIVE DISORDER (OCD)

An anxiety disorder characterized by intense, unwanted thoughts and rituals that are beyond an individual's control, such as hand washing, hoarding etc.

OCCUPATIONAL THERAPIST

A licensed professional who provides evaluation and therapy related to meaningful activities of daily life, such as self-care skills, education, work, or social interaction.

OPPOSITIONAL DEFIANT DISORDER (ODD)

A psychiatric disorder characterized by two different sets of problems, one of which includes aggressiveness, and the other a tendency to purposefully bother and irritate others.

PARENT CONSULTANTS

Parents or family members of children with special health care needs, who have experience/knowledge about resources, supports and services, and provide the unique family perspective necessary to promote family-centered services.

PEDIATRICIAN

A medical doctor who specializes in the general medical care of children.

PHYSICAL THERAPIST

A licensed professional who provides evaluation and therapy related to physical and mechanical means, such as massage, regulated exercise, water, light, heat, and electricity.

PRADER-WILLI SYNDROME

A syndrome diagnosed by a genetic test and often associated with impulsive eating, compact body build, underdeveloped sexual characteristics, and poor muscle tone. Other characteristics can include delays in speech, motor control difficulties, feeding problems in infancy, sleep disturbances, skin picking, temper tantrums, and a high pain threshold.

PROCEDURAL SAFEGUARDS

Rights specified by state and federal laws for parents of children in Early Intervention to encourage parents to play an active role in the decision-making process of their child's education.

PROMPT

A verbal or physical support that helps the child get through the action.

PSYCHIATRIC DISORDER

A mental, emotional, or behavioral disorder.

PSYCHOPHARMACOLOGIC TREATMENTS

Medications used to treat psychiatric conditions.

PSYCHIATRIST

A medical doctor who specializes in the diagnosis and treatment of mental disorders.

PSYCHOLOGIST

A non-medical doctor with a Doctor of Philosophy (PhD) or a Doctor of Psychology (PsyD) who specializes in the diagnosis and treatment of mental and emotional problems.

REHABILITATION

The restoration of or improvement in an individual's ability to perform functions such as activities of daily living.

SEIZURE DISORDERS

A seizure involves an involuntary body movement including limbs, head or neck.

SECRETIN

A hormone produced by the small intestines to help the body in the digestive process.

SENSORIMOTOR

Function in both sensory and motor aspects of bodily activity.

SERVICE COORDINATOR

Individual assigned to each family in Early Intervention to provide a single point of contact for the family to obtain services identified in the written Individualized Family Service Plan and to provide assistance as needed.

SEMANTIC-PRAGMATIC DISORDER

A disorder characterized by delayed language development problems. Symptoms included: learning to talk by memorization, repeating phrases out of context, difficulty following conversations, and difficulty understanding questions.

SPECIAL EDUCATION

Educational services for students with disabilities age 3-21 years of age, required by law to ensure the provision of a free and appropriate education designed to meet a child's unique needs.

STIMMING

An individual's fixation on an object or part of the body.

TOURETTE'S SYNDROME

A neurological disorder characterized by language and physical tics.

UNIVERSAL SCREENING

A screening at birth for specific metabolic conditions provided at all birthing hospitals in Rhode Island under the administration of the Rhode Island Department of Health.

WILLIAMS SYNDROME

A rare disorder caused by an abnormality in chromosomes which occurs at random and can effect brain development in varying degrees, combined with some physical effects and problems.

Acronyms

AARC

Autism Asperger's Resource Center

ABA

Applied Behavioral Analysis

ABC

Autism Behavior Checklist

AD

Autistic Disorder

ADD

Attention Deficit Disorder

ADHD

Attention Deficit Hyperactivity Disorder

ADI-R

Autism Diagnostic Interview-Revised

ANI

Autism Network International

AIT

Auditory Integration Therapy

APD

Auditory Processing Disorder

ARI

Autism Research Institute

AS

Asperger's Syndrome

AS

Autism Spectrum

ASA

Autism Society of America

ASD

Autism Spectrum Disorder

BD

Behavior Disorder

CAN

Cure Autism Now

CARS

Childhood Autism Rating Scale

CASSP

Childhood Adolescent Service System
Program

CEDARR

Comprehensive Evaluation Diagnosis
Assessment Referral and Re-Evaluation

CDC

Centers for Disease Control and Prevention

CHAT

Checklist for Autism in Youngsters

CPR

Cardiac Pulmonary Resuscitation

CSA

Center for the Study of Autism

DAN

Defeat Autism Now

DD

Developmental Disorder

DD

Developmental Disability

DHS

Department of Human Services

DOH

Department of Health

DSM

Diagnostic Statistical Manual

DSM-IV

Diagnostic Statistical Manual – Edition 4

DTT

Discrete Trail Training

DX

Diagnosis

EEG

Electro Encephalo Gram

EI

Early Intervention

ESL

English as a Second language

ESY

Extended School Year

FAPE

Free Appropriate Public Education

FAQ

Frequently Asked Questions

FEAT

Families Effective Autism Training

FOP

Family Outreach Program

FV

Family Voices of Rhode Island

FXS

Fragile X Syndrome

GARS

Gilliam Autism Rating Scale

GFCF

Gluten Free/Casein Free

HBTS

Home-Based Therapeutic Services

HFA

High Functioning Autism

HIPPY

Home Instruction Program for Preschool Youngsters

IBT

Intensive Behavioral Training

ICD

International Classification of Disease

IDEA

Individuals with Disabilities Education Improvement Act

IEP

Individualized Education Program

IFSP

Individualized Family Service Plan

LD

Learning Disabled

LFA

Low Functioning Autism

MDT

Multi-Disciplinary Team

MR

Mental Retardation

NAAR

National Alliance for Autism Research

NACD

National Academy of Child Development

NICHCY

National Information Center for Children and Youth with Disabilities

NIH

National Institutes of Health

NHPRI

Neighborhood Health Plan of Rhode Island

NLD

Nonverbal Learning Disorder

NOD

Not Otherwise Specified

NOS

Not of Specific Origin, Not Otherwise Specified

NT

Neurologically Typical

NVLD

Nonverbal Learning Disability

OASIS

On-line Asperger's Syndrome Information and Support

 OCD

Obsessive-Compulsive Disorder

ODD

Oppositional Defiant Disorder

OSCIL

Ocean State Center for Independent Living

OT

Occupational Therapy

PAT

Parents as Teachers

PASS

Personal Assistant Services and Supports

PARI

PARI Independent Living Center

PECS

Picture Exchange Communication Systems

PDD

Pervasive Developmental Disorder

PPEP

Pediatric Practice Enhancement Project

PSN

Parent Support Network

PT

Physical Therapy

RIARC

Rhode Island Association for Retarded Citizens

RIPIN

Rhode Island Parent Information Network

SERTS

Social Communication, Emotional Regulation
and Transactional Supports Model

S & LP

Speech and Language Pathology

SLP

Speech and Language Pathology

SI

Sensory Integration

SI

Speech Impairment

SSI

Supplemental Security Income

ST

Speech and Language Therapy

TEACCH

Treatment and Education of Autistic
and Related Communication-Handicapped
Children

TS

Tourette's Syndrome

VNA

Visiting Nurse Association

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